A.

Why Parents of Disabled Children Choose Special Education

A study of the experiences of parents caring for a disabled child at home, who have chosen a special school

by

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Declaration of Confidentiality

Throughout the thesis the names of people, places, establishments, and organisations have been substituted by pseudonyms to maintain the anonymity of all participants.

Abstract

This study was concerned with establishing why parents caring for a disabled child at home chose special schools. The method used was to survey parents of disabled children attending one of the three special schools run by the Acorn Society. The survey identified two themes. These being, that there was a gender differential suggesting that mothers were most closely involved with the care of disabled children and, that the decision to send a disabled child to a special school was measured and balanced. This was contrary to the pre-dominant view put forward in relevant literature, so, the research set out to identify the reality behind the choice of a special school.

A qualitative approach was adopted using semi-structured interviews, focusing on the issues arising from the initial survey.

The interview data demonstrated that mothers were the primary providers of care, support, and assistance, for disabled children living at home. Special schools, it was concluded, provided a level of emotional support and practical assistance, which went some way towards substituting for the absence of support from other sources. However, the situation has to be considered within the context of the twin movements of inclusive education and disability rights. The conclusion was made that there was little evidence to suggest that parents' needs would be met by their disabled child being included in mainstream education. However, it was also concluded that the present system of special education failed to meet the developmental needs of disabled children and young people. The two positions were seen as being diametrically opposed. A way forward was suggested which would, (a) offer the opportunity for disabled children and young people to acquire a positive identity, premised on the concept of disability as a unique culture, and would, (b) offer parents an appropriate level of support.

Introduction

This thesis, in many ways, represents a journey. A journey that sees a firmly held ideological view, modified by the experience gained as a consequence of conducting empirical research.

The genesis of the thesis can be traced back to the mid 1980's. I had acquired an impairment in the late 1970's, a consequence of which was a career change which saw me move from being a commercial sales representative, to become a worker with visually impaired people in the employ of a social services department. By 1986 my career had progressed and I took on the role as manager of a project to develop a resource for disabled young adults. It was at that point that the issue which was to form the basis for this thesis forcibly struck, and perplexed me.

It would be useful, at this early point, to provide a note on terminology. The social model of disability will be discussed in some depth later, but it should be acknowledged that the term 'impairment' refers to an intellectual, sensory, or physical difference; whereas 'disability' refers to a socially constructed identity which results in individual and institutionalised acts of discrimination. Not all texts will use the terminology in this way but they will be applied according to the above definitions in all my original discussions.

Defining the terms in such a way also points to the way that, during that time, my identity as a disabled person had taken form, as my experiences enabled me to make sense of my world and my reconstituted identity within it. Having been able bodied I, somewha1t presumptuously it could be said, felt I understood why a person would want to return to an able bodied state. Furthermore, because I had changed from being able bodied to being disabled I considered that I knew how able bodied people thought of disabled people. It was partly as a result of that experience that I was motivated to

take on the project for disabled young adults because I felt that if I could combine that experience with my understanding of the social construction of disability, then, maybe, I could create a philosophy which would underpin practice, and thereby enable disabled young people to take control of their own destinies.

The project was sponsored by a regional charity (The Acorn Society), the local social services department, and an organisation comprising parents with a disabled daughter or son. The parents' organisation had successfully lobbied for the project which they felt was necessary because the overwhelming majority of the young people had attended special schools and the parents group considered the options available to their daughters and sons on leaving school to be inappropriate.

Although, over a period of years, I had visited a number of special schools throughout England this was my first close involvement with numbers of disabled young people who had received their education in special schools.

Additionally, as project leader, I found myself in close contact with parents of disabled children. The nature of this contact tended to be either as an advocate for a young person who requested that I approach their parents on their behalf, or, I found myself defending a service user's planned action to parents who frequently became aggressive towards me.

This generated within me the notion that parents were largely obstacles to any progress their daughter or son might make. The pervading culture amongst professional colleagues was also one which saw parents as the reason why disabled young people could not take their rightful place in society as independent adults. My attitude to parents was further fuelled by my reading, of literature, notably (Finkelstein (1981) and Oliver (1983), relating to disablement.

These then, were the two factors which raised questions for me. Namely, why did special education persist and what role did parents play in that continuation?

Further reading suggested that the phenomenon of special education for disabled children had existed for over a century and whilst there had been some decline:

> 'In 1996 the special school population declined to 88,849, or 1.40% of all 5-15 year olds - the lowest ever percentage for England'. Norwich (1997:4)'

special schools still occupied an established place in the British education system. Furthermore, the separation of disabled children from their non-disabled peers for the purpose of education has assumed a negative status, so that disabled children who are educated in special schools are perceived as receiving an inferior education which ill-equips them for life after school. John summarised that view thus:

> 'The established view of appropriate education is based upon this characterisation [the natural consequence of possessing an impairment is an inferior capability to able bodied people] so disabled school leavers have consequently only been prepared for a life of limited personal autonomy. Special education designed with these implicit assumptions, disabled people have repeatedly pointed out, is simplistic and whilst logically consistent with our imagined permanent dependency provides inappropriate and often irrelevant training for full participation in society.' (undated:1)

The literature indicated, as it continues to do, that the debate about special education has become polarised along a line which, on the one hand, puts forward the view that some form of specialised provision within a separate setting is, and is likely to remain, necessary for some children. This view is summarised, as follows, by Rogers in his commentary on the Warnock Report (1978):

> 'However, special schools would continue to have a vital role in, for example, offering separate provision for children with particular needs; giving intensive

> specialized short-term help, sometimes at short notice; or developing as resource centres, for all the teachers in the area, for curriculum development and in-service training or possibly concentrating on rare or complex disabilities.' (1980:264)

On the other hand the view is that all children should be educated inclusively, subsequently articulated by Booth and Ainscow thus:

> 'Our view of inclusion, then, ... involves the processes of increasing the participation of students in, and reducing their exclusion from, mainstream curricula, cultures and communities.' (1998:2)

My earlier reading had pointed to an explanation as to why there was a need for the project I led, because it highlighted the consequences for disabled children of being educated in a segregated setting. Oliver (1983, 1990), Barnes (1990), Mason (1992), John (1988), for example, all identified the negative results of segregated schooling. So, the need for a 'bridge' between leaving special school and joining the adult world was apparent.

There were, however, different perspectives on the role that the project should perform.

It was then that I got a clearer understanding of differences between what parents wanted for their daughters and sons, and what the Acorn Society and the social services department saw as being the role of the project. It was dealing with those differences which provoked my consternation towards parents.

The parents generally projected the view that the project should provide a safe environment in which their children could meet with other young people and take part in activities. The local authority social services department was committed to the concept of preparing young people for adult life whilst the third partner, the Acorn Society, was concerned with ensuring that the grant was paid and that the establishment made sufficient money. Significantly,

some might argue, the key aspect of such a project, namely, it's philosophical underpinning, was left largely to myself and the staff to develop. I mentioned above the significance I attributed to both my personal experience and theoretical understanding of disability, and it was those factors, along with my increasing understanding of, and commitment to, the notion that disability is socially constructed, which provided the ideological thrust for the projects' philosophy. This caused me some soul searching because, if I believed disability to be socially constructed then surely I would have a problem at an individual level in alleviating the product of the oppression. However, one role I felt the project should pursue was that of politicising the young people, without proselytising them. This was to prove to be the source of continuing conflict with parents. I lead the project for six years and throughout that time I was perplexed by the mind set of the young people. Not only did they seem resistant to attempts to raise their awareness of their social position, but also seemed devoid of anything one might call, however diluted, 'ambition'.

A particular difficulty I encountered was endeavouring to encapsulate that 'attitude' in words. 'Apathy' did not adequately describe it. Nor did 'indifference', 'complacency', or phrases such as 'lack of motivation'. It was as if the young people had no notion of a future in which their life would, or could, be any different. The one common factor to the overwhelming majority of users was that they had all attended special schools for 'handicapped' children. Was this, I continually asked myself, the reason for the mind-set of the young people?

This was to be a motivational factor as I sought an answer to what I increasingly came to see as a conundrum. That being: 'why, if special education was plainly failing to prepare disabled young people for adult life, did parents of disabled children not challenge the segregation of their children?'

The literature suggested that parents were the hapless victims of a process of socialisation dominated by medical professionals. A view put forward by Barnes:

> 'Institutional discrimination against disabled people is ingrained throughout the present education system. The data show that most of the educational provision for disabled children and students remain basically segregative, is dominated by traditional medically influenced attitudes, and commands a low priority within the education system as a whole. As a result, rather than equipping disabled children and young people with the appropriate skills and opportunities to live a full and active adult life, it largely conditions them into accepting a much devalued social role and in so doing condemns them to a lifetime of dependence and subordination. In addition, by producing dependence in this way it helps to create the negative stereotypes by which all disabled people are judged, and therefore a firm basis for the justification if institutional discrimination in society at large.' (1991:28)

Indeed, I well remember going to a special school where I was shown a white board by the Deputy Headteacher on which all the pupils attending the school were listed, not by name, but by medical diagnosis. Accordingly there were so many with Cystic Fibrosis, so many with Cerebral Palsy, so many with Spina Bifida, and so on.

As a result of these experiences, and my reading, I was left with an unequivocal belief that segregated education should be abolished, and that the problems faced by disabled people who had been educated in segregated settings would be greatly diminished if all children and young people received their education alongside one another in inclusive settings.

Initially, I was of the opinion that because special schools were so evidently providing a negative and oppressive experience for children with an impairment then there must be some external influence causing parents to choose that route for their child. I therefore decided to explore the role played by professionals in that decision. I had a hypothesis which placed the blame

at the door of inflexible professional experts who offered parents no choice and steered them into choosing a special school. Consequently, I decided too that my research should examine the way that influence was exerted.

My initial strategy was to firstly survey a group of parents of children attending a special school run by the Acorn society to establish the role played by professionals in their choice of school. I then planned to go on and compare that with data obtained from parents of children at a local authority school with an integrated policy. The research would then move on to seek the views of a range of professionals to ascertain how they saw their role in the selection process. However, when I received the first batch of returned questionnaires I was to comprehensively revise my position.

The responses indicated that my early hypothesis was flawed and that far from parents being strongly influenced by professionals there was every indication that parents gave considerable thought to their choice, and were active in the decision on which school their child should attend. The following quotation from one questionnaire is representative of many of the views contained in the first batch of returned questionnaires:

> 'We wanted our son to be taught by specialist staff who were skilled and experienced in the management of autistic children. We also wanted small group teaching, emphasis on an individual learning programme, and high speech therapy input. None of this would have been possible in a mainstream school. Our son does not have the skills to cope in such a setting, nor in a moderate learning difficulties unit - yet. Language units cannot cope with or understand the problems caused by autism - they only deal with language disorders. In short, we had no other choice. We cannot think of a more suitable option at the present time and there are no facilities for children with autism in the borough in which we live. We only wish he could be integrated into a mainstream setting with adequate support from trained staff.'

These did not strike me as the responses of 'hapless victims of socialisation', nor did parents appear to be unthinkingly following the directions of professionals. The opinions on the questionnaires clearly identified that there were several factors important to parents, which needed to be explored in some depth. However, this will be developed further in Chapter 1.

The responses also indicated that there was a substantial gender imbalance in the respondents, which was also to influence the information I sought..

I began to examine my view of parents and came to question the 'hapless victims' explanation. This resulted in my deciding that, if I was to stand a chance of solving the conundrum of 'why parents choose segregated schools', then my research would have to address the conundrum directly. The best way, I considered, of doing this, and the route I adopted, was to ask the parents themselves why they had made the choice. I then hoped that by placing the particular experiences of the Northern parents within the wider social and political context, I would be able to produce a rational explanation for choosing a special school. Having produced an explanation, I anticipated being able to propose future strategies based on my analysis. I believe I have done this, and that the thesis provides affirmation that empirical research conducted with an open, receptive, and flexible methodology does produce fresh insights into social phenomena, and can lead to the generation of new ideas.

Consequently, the thesis will be structured in such a way that the 'journey' is navigated through the process of certainty, through uncertainty, and then to a unanticipated destination.

CHAPTER 1 provides a detailed analysis of the research design which provides an explanation of the decision to re-focus the research, and the consequences that had for the subsequent research process. This leads to a critical analysis of the methods employed to collect the data along with their

appropriateness and effectiveness. Issues concerning research methodology form an essential component and the relevance of the selected approach is evaluated.

Useful data was produced by questionnaires used to survey parents with disabled children attending educational establishments run by the Acorn Society. These data provide background information on the Northern parents and, **Chapter 2** ensures that the Northern parents do not appear as an abstract group of people but can be located within a frame of reference provided by a range of data on the composition of the sample and elements with significance for parents caring for a disabled child.

The primary empirical work was conducted with the Northern parents. Their accounts provide the rich source of material which enables subsequent discussions and debates to take place, and for conclusions to be reached. That material - the views, feelings, and experiences of the Northern Parents - forms the substance of **Chapter 3**. The accounts are organised and presented at length and in detail. Accordingly, a picture of what the lives of the Northern parents are like is created. A discussion summarising the major themes arising from the accounts concludes the chapter.

Chapter 4 takes the findings from Chapter 3 and places the experiences of the Northern Parents within the wider context of existing research and literature. This location of the Northern Parents within the wider context provides an indication of similarities and differences between their experiences, and those of other parents in similar circumstances.

It has been acknowledged that special education is a complex social phenomenon so to treat parents in isolation would be to ignore the influence of history and social forces. The experiences, therefore, of the Northern parents, and those of other parents caring for a disabled child, must be located within a social and political context. **Chapter 5** will, therefore,

consider the role played by special education in Western societies and will articulate and debate the concepts of disability culture, identity, choice, and consumerism.

Chapter 6 will draw the different themes together and provide an analysis which posits answers to the questions posed above. The chapter also proposes a model for special schools in the future which is a response to unresolved dilemmas exposed by the research and the subsequent analysis.

The final comment of the thesis will be a response from the writer as to whether the journey has been worthwhile and if a safe destination has, indeed, been reached.

A

Chapter 1

The Study

INTRODUCTION

In the introduction the impact of special education on disabled young people was identified as being a factor which had stimulated a study into reasons for it's continued existence. Indeed, a body of opinion can be identified, from academics, parent action groups, and disabled people, which argues for the abolition of special schools. A number of reasons for its continued existence are put forward; Middleton (1999) suggests the socialisation of parents of disabled children, Oliver (1987. 1990, 1996) argues that structural factors are the reason. Disabled people who attended special schools Smith (1994), Barnes (1996), French (1993), suggest that professionals exert influence over parents or, parents just assumed that special education was the natural way to educate children with impairments. These propositions were a key element in the development of a hypothesis which pointed to professionals in the field of education and the assessment of special educational needs, and those associated with the provision of care and support for parents caring for a child with an impairment, as exerting influence on parents. This influence, it was believed, channelled children with impairments into special schools, rather than looking creatively at ways in which children with impairments could be educated in mainstream schools. This could be seen as a somewhat simplistic view which failed to recognise that, for the special school system to have continued, thereby withstanding the body of criticism levelled at it, there must have been reasons behind the support for it's continuance. However, that aside, it provided a starting point for the research and prompted an approach to the Acorn Society.

The decision had been taken that the first stage of the research should be to obtain information from parents with children at special schools. Accordingly the Acorn Society was approached. A senior executive of the Society considered the approach and agreed that contact could be made with the heads of the establishments providing education for children with impairments.

The Acorn Society is a charity located in the North West of England which has been providing services for 'disadvantaged' children since 1870. It was considered to be suitable for this research because it ran three establishments providing special education for children with impairments. Additionally, the society currently provides a range of services including residential provision for children being 'looked after' by local authorities under the Children Act 1989, a guardian ad litem panel, a children's rights service, a mediation service, a special educational needs parent partnership, and a respite service for disabled young people.

Because of the three special educational establishments, the Acorn Society was considered to be ideally placed to enable access to parents who had children receiving an education at a special school. Implications this choice might have for the research were acknowledged and will be discussed below. However, a short summary of the characteristics of the three establishments will give a sense of the overall nature of the Acorn Society's special education provision.

THE THREE SPECIAL EDUCATIONAL ESTABLISHMENTS

The Acorn society ran three distinct establishments, each supplying a different educational provision, so each establishment will be considered separately.

BEECH SCHOOL (THE SECONDARY SCHOOL)

Beech School had evolved over the history of Acorn and, with its roots in the 'Home for Crippled and Incurable Children' which had opened in 1890, it occupied a unique position in the society's history. Consequently, it had for many years formed the main element in the service for disabled children and young people provided by Acorn. At the time of the research Beech was facing financial difficulties because of competition and diminishing numbers of prospective students. This was not a new phenomenon for Acorn and it had responded to the need for change by adopting a more flexible approach to the facilities provided by Beech. In the early 1990's it opened a hydrotherapy pool, so that students who had previously been transported to a hospital setting to receive hydrotherapy could now receive it on the school site. It was also anticipated that there would be opportunities to raise revenue by sub-letting the pool to other organisations.

Beech improved it's buildings and physical surroundings through a programme of alterations, decoration and adaptation. Additional computing equipment had been purchased to improve students' capacity to communicate and access the curriculum. The school had been innovative in it's approach to the National Curriculum, and had been a pilot in research conducted by the Department for Education, on how the National Curriculum could be accessed by children with special educational needs which significantly limited their capacity to access the National Curriculum in it's undiluted form. Consequently Beech was able to adapt the National Curriculum to enable individual programmes to be developed for students. This option is available in the Education Act 1993, 1994 Code of Practice, which allows head teachers to apply for modifications to the National Curriculum. This relates to stage 3 in particular, but is rarely used as the Code of Practice emphasises the child's needs, and therefore offers scope outside the formal application procedure.

However, despite these measures the school continued to experience falling rolls so that in January 1996 the number of students attending the secondary school was 25.

One consequence of the need to maintain sufficient numbers on the school roll was that when Beech was approached by the Local Education Authority (LEA) and asked to take a small number of children with 'speech and communication difficulties', it agreed. The LEA had experienced problems providing for the special educational needs of three such children within mainstream schools. Each was of secondary school age, and had been diagnosed as being autistic. The needs of the small group of children with autism was different to those of the other students already attending Beech, inasmuch as the needs of the three new students were seen to be predominantly for speech therapy and closely monitored programmes of learning, rather than the existing Beech students whose needs were seen as predominantly being physical care, para-medical therapies and personal support. Whilst the three students with autism were at Beech they were taught as a discrete group, until they subsequently moved across the campus to a new establishment catering specifically for children with autism, opened by the Acorn Society.

ASH SCHOOL (THE UNIT FOR AUTISTIC CHILDREN)

The unit for autistic children opened in 1993. The head teacher was an educational psychologist and had been instrumental in the planning of the unit before it opened. The unit moved into premises formerly occupied by the Society's Extended Education Unit and commenced with a small number of pupils. Projections of growth had not been misplaced and by 1996 the unit had 33 pupils. Although the pupils who had attended Beech were of secondary age, Ash took children from 5 to 11.

The students at Ash, although broadly defined as having 'speech and communication difficulties', have a range of diagnosis. Whilst, these include Autism and Aspergers Syndrome, it would be fair to say that many of the students have proven to be difficult to diagnose. Indeed, the concept of a 'diagnosis' is, in itself contentious in this context, inasmuch as the culmination of an assessment process

diagnosing the cause of speech and communication difficulties is problematic, and the 'label' of autism can be used as a blanket term in the absence of precise definitions of causality. Consequently, students have individualised programmes which endeavour to combine strategies aimed at developing each student's capacity to communicate effectively with others, with educational programmes within the National Curriculum. Subsequent data will demonstrate that Ash was attracting children from a wide geographical area, all of whom travelled on a daily basis. Ash concentrates on providing customised programmes for each pupil with a low pupil/student ratio. This enables them to focus on individual communication needs with the additional input of high levels of speech therapy.

The third establishment grew out of the Extended Education Unit mentioned above and became Oak College.

OAK COLLEGE (A COLLEGE FOR DISABLED STUDENTS AGED OVER SIXTEEN)

As mentioned above, part of the secondary school had comprised an extended education unit which enabled students to continue in education until the age of nineteen. Education authorities retain responsibility for the education of young people who are the subject of a statement of special educational needs under the Education Act 1993 until the age of nineteen. It was a consequence of this, and the absence of local provision for disabled young people over the age of sixteen that had previously led Acorn to open the extended education unit. Additionally, the inception of the Higher and Further Education Funding Council, and a separation between secondary and post-sixteen education introduced in the Higher and Further Education Act 1992, made separation of it's post-sixteen provision from it's secondary provision inevitable, if enforced closure was to be avoided.

In 1996 Oak College had 26 students with a range of physical, sensory and intellectual impairments. They all travelled to the college on a daily basis and came from several local authority areas. The school espouses an ethos of developing student autonomy and independence. It offers a range of educational programmes, mostly within the General National Vocational Qualifications framework. As with it's two sister units, Oak College offers para-medical support and a range of therapies.

That is a brief summary of the three special educational establishments which the children of the parents in the study attended. They can, arguably, be seen to embody many of the components associated with special schools for disabled children. That is, they are separate from their mainstream counterparts, and in the case of Beech and Ash are located on a secluded suburban woodland site, and they provide all services within the school. Consequently the three establishments provided the ideal context in which to explore the reasons behind parents choice of a special school and the section will now continue documenting the research process.

The head of Ash School, was approached and agreed to distribute questionnaires, via students, to parents. As stated above, the aim of the questionnaires had been to obtain information from parents on aspects relating to their child's attendance at a special school. Within the questionnaires there was an open question asking parents to highlight why they had chosen the institution they had for their child. Examination of the completed and returned questionnaires proved to be pivotal in the direction the research was to subsequently take.

A notable feature of the returned questionnaires was that the vast majority were completed by mothers. This prompted consideration to be given to the issue of gender. This was, at that stage, uninformed but when combined with a further characteristic of the returned questionnaires, it would prove to be telling in the decision to change the focus of the research. That was, to concentrate exclusively on parents themselves as the means of finding out why parents choose special schools.

In the questionnaires the parents provided information which indicated that they were having to provide high levels of care for their child, that they appeared to have received little assistance in the choice of a school from either social work or para-medical professionals, and that far from appearing to be hapless victims of socialisation, there emerged a distinct impression that parents had concerns about their child's attendance at a special school. The following comment demonstrates this and indicates a depth of feeling which was both chastening and influential in the decision to change focus,

This mother had added a note with the questionnaire in which she apologised for the late return of the questionnaire and for not being able to participate further in the research. She then went on to say:

> 'One other thing I felt I had to add was that I was upset by your referring to *Ash* as an "institution" in your letter. It is in fact a school, admittedly not the sort of school we would have wanted for our son, but we did not have a choice. There isn't a day goes by when I don't wish our lives could be normal and our son could be in an ordinary school along with his older brother!'

The strength of emotion in this statement is evident, and humbling, however, here was a mother who fervently wanted her son to be educated in the mainstream yet 'did not have a choice' and, furthermore, she did not consider that her life was 'normal'. Several other common factors featured in the returned questionnaires. Atmosphere and environment were frequently mentioned:

> 'Ash had a lovely atmosphere, the children really loved the school. Ash is one big happy family. Nothing is too much trouble and we are all included in what is going on. The education standard is top rate, and the children work very hard, because they want to. There is no pressure put on the children so they do their best.'

> 'A very nice school. The environment and teachers are good for my daughter.'

> 'The atmosphere and the environment are very suitable for my child.'

There was also evidence that parent's had thought about the choice in some depth:

'Because we wanted special and the correct help and support four our son, a programme of education, high staffing in class, speech therapy etc. This cannot be given in mainstream.'

'My husband and myself have been constantly striving to find the right placement for our child and Ash was the only one that we though would meet our son's needs.'

Whilst there was evidence that choice had been exercised there was also evidence to suggest that choice was limited and alternatives were not suggested by local education authorities

'It's the only day autistic school in ****shire. The school the education department wanted me to send Harry to was very unsuitable for an autistic child. So I said I only wanted Ash for Harry. In the end he went there. The school's only been open for three years now and Harry has attended two years. He has one-to-one learning, which is very important for Harry, and has come on a long way since starting there, so we are pleased with the school.'

'Because it was the only establishment that offered the facilities to help our son with specialist staff, reasonably near to home in a pleasant environment. No other options were suitable or acceptable.'

One response was stark in it's simplicity:

'It was more or less fobbed on me. I was not told by ****shire that I could look at other schools'

So, on reflection there appeared to be a range of factors influencing parents and whilst it was evident that there was little choice available parents were able to clearly articulate what aspects of a school they considered to be important to them. However, although the reasons for parent's choice of a special school could be identified, the degree of importance attached to those factors and the underlying experiences which had led parent's to conclude that those were the important elements they looked for, were not evident. So, after considerable thought, the rationale for the future focus of the research became the need to resolve the issue of why did there appear to be no choice, what did parents mean by a 'good atmosphere', why was staff expertise only perceived as being available in a special

school, how important was the implication that parent's were included in school life? Additionally, what was different about the lives of parents, particularly mothers, which caused one mother to consider her life as abnormal?

This chapter will, therefore, discuss the way in which the research was designed so that the views and experiences of parents, hereinafter known as the 'Northern parents', could be obtained and, specifically, to identify if the roles performed by parents caring for a child with an impairment were differentiated by gender and, if so, what function, if any, did special schools fulfil?
Firstly, methodological issues will be discussed so that the underpinning philosophy of the research can be identified. Secondly, methods chosen for the collection of data will be analysed. This analysis will include critical consideration of the key elements employed during the research process.. Those being:

1. The sample.
2. The questionnaires.
3. Questionnaire data analysis.
4. The interviews, including transcription.
5. Ethical considerations.

So, the next section will set out the parameters which governed the scope of the research and determined the process it would follow.

THE RESEARCH METHODOLOGY

It has been argued that methodology, methods, and paradigms are frequently confused and used interchangeably (Sarantakos 1998). One result of this is that research can be presented as a neutral process of data collection which establishes the realities of social behaviour. But research cannot be a neutral process, although

the traditional view of quantitative research would tend towards the view that 'true' research is objective and is the best way to get at the truth. Nevertheless, qualitative research has become a significant methodological approach in social research so this section will consider the factors which determined the choice of a predominantly qualitative methodology and issues relating to this choice.

Considerable thought was given to the methodology which would underpin the research. The view was held that the most effective way of establishing why parents chose special schools would be to find out about their feelings, their individual recollections, their accounts of events surrounding their daily lives, and issues which concerned them regarding the care of their disabled child. Having established this, the data would then need to be interpreted so that the views of the Northern parents could be subjected to analysis on the basis of their generalisability.

Qualitative methods are rooted in sociological theories, such as symbolic Interactionism, ethnomethodology, hermeneutics, and phenomenology, and because of this they are premised on the notion that the world does not consist of sets of rules which govern behaviour. This differs from positivist approaches which are based on the belief that social phenomena can be studied scientifically and, therefore, rules can be discerned which 'determine' social behaviour. Qualitative approaches take the view that people interpret the world in different ways so, for research to provide explanations of social phenomena, we need to understand how people make sense of 'their' world. Referring to the tradition of phenomenology, Sarantakos (1998), illuminates this point:

> 'The perception of the world as being created by people, the notion of natural attitude or natural standpoint, the process of getting down to the essence of people, the perception of reality through the minds (consciousness) of the respondents and the process of bracketing are a few examples.' (:49)

So, it can be seen, that this approach would provide a framework for getting at the Northern parent's 'perception of reality'. Furthermore, Beresford *et al* (1999),

reviewing evaluative research methodologies, commented that '*we cannot ignore the power of personal experiences of disability*.' (:24)

However, the distinction between quantitative and qualitative methods of data collection is often too arbitrarily constructed and crudely interpreted. Vogt (1999:230), refers to qualitative research, somewhat dismissively, as *'a residual category for almost any kind of non-quantitative research.'* although he qualifies this somewhat by saying *'The qualitative/quantitative distinction is often overdrawn.'* (Ibid). This points to a difficulty with endeavouring to locate a research process within a particular methodology. This is highlighted by this study which adopted different approaches at different stages in the data gathering process. Initially survey data was collected and, subsequently, personal accounts were acquired. This would point to two contrasting approaches, that is, in the case of the former a quantitative approach, and in the case of the latter a qualitative approach. However, rather than being contradictory, the two approaches complement one another as the former provided the context and preliminary information which, in turn, informed the latter. Indeed, rather than becoming involved in a debate on the reality of knowledge and how it is generated, the study took a pragmatic approach by using the research tool which it was felt would provide the best way of achieving the required results, those being the views of the Northern parents. By adopting this approach it was hoped to avoid becoming embroiled in a debate in which qualitative methodology is criticised by those who espouse positivism which, it is argued, has rigour, is testable, has samples on large scale and, therefore, generalisations can be made. Qualitative research, is often presented as possessing none of these attributes and, consequently, has no significance as a mode of social research. Whilst recognising the criticisms of qualitative research this study wished to avoid a rigid positivist approach which, it is argued, leads to a restricted, selective, and narrow view of the world. Beresford *et al* supply a telling commentary in support of that view:

> 'Researchers who focus on quantitative methodologies without taking account of the feelings, aspirations and basic humanity of those they study are not just acting unethically, they are likely to produce sterile research.' (1999:24)

Note had also been taken of criticism of quantitative research from within feminism, where the argument is made that positivist approaches have ignored the oppressive character of society, and the way in which patriarchal structures impose knowledge has not been challenged. Although feminist research has used both quantitative and qualitative approaches during its development, it has come to look increasingly towards developing original ways of gaining information which fall within a qualitative definition.

> 'In challenging positivism's epistemology - the methods through which it acquires knowledge, and ontology - the assumptions underpinning its theoretical base, feminists and black activists have exposed the hollowness of its claims to a 'scientific, objective, neutrality' (Bryant et al, 1985, Stanley and Wise, 1983). They have demanded that their voices be heard. And their critiques have included alternative paradigms which can provide a more accurate rendition of reality.' Dominelli (1997:18)

It is, therefore, only as a result of approaches which enable the real experience of individuals and oppressed groups to emerge clearly and coherently, that a true and full understanding of the social world can be achieved. So, whilst subscribing to both points of view, that is, the sterility of pure positivist research, and the need for an 'accurate rendition of reality', a combined approach will be seen to have been adopted which, it is believed, was most appropriate to the situation.

Indeed it was hoped that by finding out what the Northern parents thought and felt then the assumption that they were either being manipulated by care and education professionals with covert motives, or were socialised into accepting segregated schooling as the proper way in which their disabled child should be educated would be interrogated. This approach is based on the concept of developing theory on the basis of empirical research, thereby the theory is 'grounded' in the reality of social experience rather than hypothesised theory. This is succinctly put by Abbot and Sapsford:

> 'Good research tries not to take for granted what is assumed by common-sense. It tries to argue rigorously, according to the 'rules of evidence' (1998:4)

It is also argued by some feminist and disability researchers that research should be emancipatory. Research, therefore should only be undertaken if it will result in a positive outcome for the research participants. However, the debate has gone beyond the notion of reciprocity. Oliver (1992) arguing that research should challenge the existing oppressive social order rather than be the province of academics who alienate participants through a process of abstracting and individualising human experience. So, it is argued, research needs to be part of the solution to existing oppressive social orders and not merely an objective observation. Consequently, the researcher needs to ask how the research process will further the process of empowerment, and to be a part of that process. At the heart of this debate lies the issue of who controls the research agenda and who stands to gain from it. Indeed, this is an issue which should concern all researchers probing into peoples lives, experiences and thoughts, and care should be exercised so that the rights of research participants are not abused to further the reputation and careers of researchers. The ethical dimension of this research is addressed below, but it is worth pointing out that one of the difficulties with debates such as these, is that they risk becoming purely theoretical and the purpose of conducting research is lost, for, whatever the method used the aim of research should be to further knowledge with a view to improving conditions. Not to become an esoteric domain restricted to purists and academics.

The objective of the discussions on methodology contained in this section was to identify the underlying theoretical issues associated with the chosen approaches, However, as mentioned above, the approaches used to obtain data from the parents of children attending the Acorn society's three establishments, were chosen because they provided the best tools for doing the job. It was felt that statistical data relating to family circumstances would provide a contextual framework, so a survey questionnaire was used in the initial stages. Subsequently, in order to find out the views and opinions of the sub-sample of the Northern parents, interviews were used. So, it can be seen that quantitative and qualitative approaches complemented one another and provided the best way to find out why parents choose special schools.

So, having identified how research methodology influenced the research process the next section will move on to discuss the early stages of the research process. That being, how the sampling process culminated in the identification of the Northern parents.

THE SAMPLE

The first objective of the research was to identify and access an appropriate sample. So, having determined the objective of the research, the starting point was to:

- gain access to parents of disabled children to find out if there were any common features which might provide a basis for a preliminary hypotheses, and
- recruit parents willing to be interviewed.

Following an approach to the Acorn Society a positive response was received and permission was granted to go into the establishments and talk to head teachers of the three establishments. Indeed, it was felt that elements of the research might be of some benefit to the charity to enable it to identify aspects of it's service which might be enhanced or publicised. However, this was seen as being a by-product of the research and was openly acknowledged as such.

The use of the Acorn society could be defined as 'convenience sampling' which Flick refers to as being:

> 'the selection of those cases which are the easiest to access under given conditions. This may simply be to reduce the effort. However, from time to time it may be the only way to do an evaluation with limited resources of time and people.' (1998:71)

Whilst this was one aspect behind approaching Acorn, inasmuch as the resources were 'limited' to the writer himself, the fact that a sample is convenient does not, in itself, diminish the sample's relevance.

Notwithstanding it's convenience Acorn provided access to a distinct group of people, namely 84 sets of parents caring for a child with an impairment currently attending a special school. It was, therefore, hoped that a sample could be constituted from parents agreeing to be involved in the research. However, the 'self-selection' of what was to become the Northern parents raises the issue of sample reliability. That said, a clear definition of what constitutes a 'reliable' sample is not possible but, if, on completing the research, responses indicate that the experiences of the respondents in a sample have common features, and if those features are also common to the literature on the subject, then the sample can be seen as being reliable. With the Acorn Society and the Northern parents the reliability of the sample could only be judged retrospectively once the data had been evaluated. Indeed, this turned out to be the case and the many common features which emerged from the research will be discussed in subsequent chapters.

Flick offers some thoughts on the issue of the representativeness within qualitative research which highlight the relevance of selecting the Acorn Society as the conduit, which would ensure that the sample would be able to fulfil the objective of establishing why parents choose special education:

> 'The representativeness of a sample is guaranteed neither by random sampling nor by stratification. Rather, individuals, groups etc. are selected according to their (expected) level of new insights for the developing theory, in relation to the state of theory elaboration so far. Sampling decisions aim at that material which promises the greatest insights, viewed in the light of the material already used and the knowledge drawn from it.' (1998:65)

A further issue in sampling is that of representativeness. That is, how representative were the Northern parents of the total population (those choosing special education)? Representativeness was not felt to be a significant factor because if analysis of data yielded by the research indicated commonalties, or could be 'bracketed' Sarantakos (1998), then if these were significant within the parameters of the research then the sample could be considered to be adequate. If, on the other hand, commonalties were not apparent then it would be safe to surmise that a sample of any larger a size would also be unlikely to generate themes. Furthermore,

the objective of the research was to get at the realities felt by parents caring for a child with an impairment. That reality is likely to be different for each parent and to be affected by a wide range of social factors impinging on the individual experiences of parents. And, whilst highlighting that common features would be identified, it is worth adding that the depth and richness of individual experiences runs the risk of being diluted if the breadth of a sample is such that the sheer volume of data generated, obscures the meaning derived from the detailed analysis of those personal experiences.

However having gained access to the Acorn Society's establishments a survey questionnaire was sent out and the next section will evaluate that stage in the process.

THE INITIAL SURVEY

Having gained access to the three Acorn establishments it was decided to obtain basic information on the circumstances of those parents caring for a disabled child attending one of the establishments. It was felt that the acquisition of standardised data would be the first stage in establishing common themes amongst parents and that the best instrument to achieve this would be a postal questionnaire. Whilst there are other data collection instruments, for example structured interviews and randomised face-to-face surveys, it was felt that the particular mixed format of the questionnaires used in this instance, when taken alongside the positive support provided by the school facilitating circulation via the students, would yield the best results.

However, as with all research instruments, questionnaires have their strengths and weaknesses. An examination of their use reveals that in qualitative research they are often used to survey a population prior to concentrating on a sub sample of the population in greater depth. They help to provide a range of detail and whilst

questionnaires have limitations in the scope they provide for establishing new information, their strength lies in the way they can efficiently and effectively be targeted at a large population, whilst retaining the anonymity, if desired, of the respondents. The questionnaires used in this instance can be defined as self-completion postal questionnaires, and, as such are likely to be identified more closely with quantitative methods, further underlining the point made above that research generally contains elements from both a quantitative and qualitative approach. Whilst this may be so, the position of questionnaires within qualitative research is not without complication. Writers, see Mason (1996), Newell (1993), Robson (1993), Silverman (1993), tend to separate questionnaires into two categories. Those used in postal surveys and those used as the basis for face to face interviews. The questionnaires used in this instance fell largely into the first category and proved to be a valuable tool providing a range of information.

33 questionnaires were distributed to parents with children at Ash; each one was accompanied by a covering explanatory letter, a form asking if the respondent would agree to be interviewed at a later date, and a stamped addressed envelope for the returned questionnaire. (See Appendix A)

The aim of the questionnaires was three fold.

- Firstly they would provide socio-demographic data on children attending the school and their families.
- Secondly they would highlight issues for future research.
- Finally a response sheet for completion by parents prepared to be interviewed accompanied the questionnaires.

This final objective of the questionnaires was not only to identify parents willing to be interviewed but also to gauge the response rate so that a projection could be made as to how many parents might agree to be interviewed. If numbers were considered to be too few to constitute a viable sample then a decision would have had to be made about whether other organisations would need to be approached. This would

have led to a re-evaluation of the decision to limit the research to parents of children attending Acorn Society establishments and the possible need to reassess the research objectives.

A 58% response rate was achieved with eleven respondents agreeing to be interviewed.
The response, although it might not be considered to be high, is above average.

> 'The main arguments against using postal questionnaires has generally been that the response rate is low (many postal surveys do not achieve more than a 50 per cent rate of return) and that even when respondents do complete questionnaires, their answers may be incomplete, illegible or incomprehensible.' Newell (1993:97)

Neither of these criticisms could be levelled at the returns with each one completed legibly and, overall, omitted answers were so few as to be render them inconsequential. Because the response rate was above that considered to be average and, because they were fully completed, the response rate was considered to be acceptable.

It is commonly accepted that good research should involve the piloting of research instruments, Abbott and Sapsford (1998), Punch (1998), Robson (1993), Sapsford and Jupp (1996), Sarantakos (1998), So it was that it was decided to use Ash school to pilot the questionnaires and then evaluate those which were returned, completed.

However, strict research protocol was not followed in this instance.

Robson provides support for this decision and whilst this research is not defined as a case study the principle still applies:

> 'Case studies have sufficient flexibility to incorporate piloting within the case itself. The effort needed in gaining access and building up acceptance and trust is often such that one would be reluctant to regard any case study simply as a pilot.'
>
> (1993:301)

Consequently, having decided to include Ash school parents they needed to be accommodated within the contextual data. Had the questionnaires required substantial revision then this could have presented a problem. However, as it turned out the only changes felt to be needed were changing the scalar numbers to fit in with the ranges identified in the first questionnaires. This did not affect the data but merely made it easier to extract from the completed questionnaires. Whilst the literature stresses that material acquired during a pilot should not form part of the main research findings this is, in essence, a contradiction of the benefits working within a research paradigm premised on a qualitative approach. That is, to ignore the information provided by Ash parents would be to deny its significance because of a research protocol, and whilst not arguing that protocol should be ignored *de rigueur*, sufficient flexibility should be allowed, providing it does not negate the legitimacy of the research findings. This was considered to be such a situation. The questionnaire data was the only component of the research involving Ash parents which could be considered part of a pilot but would, nevertheless, provide background information which could be compared with that of the other establishments. Accordingly, the Ash parents became part of the survey data.

Three factors stood out in an initial appraisal of the first returned questionnaires:

1. 18 of the 19 returned questionnaires had been completed by mothers with 10 of the 11 agreeing to be interviewed completed by mothers.

2. Qualitative responses [the questionnaires concluded with an open question asking respondents to say why they selected Ash School] indicated that the choice of school had been a rational choice by parents with specific reasons for the choice clearly identified.

3. Levels of personal care quantified on the questionnaires were high and correlated with mothers' category of employment, that is, the employment status of mothers, with few exceptions, was stated as 'unemployed' .

Whilst the data yielded by the survey is examined fully in Chapter 2 the rationale for identifying the above three factors at this stage is that it was just these factors which

prompted a re-examination of the prime objective of the research because the data pointed to a gender division in the care of disabled children. Furthermore, care appeared to be, in the main, provided by mothers. Consequently, the question as to whether there was a connection between the level of support provided by special schools and the needs of mothers caring for a disabled child, was raised.

Having analysed the first questionnaires Beech School was approached and a further 25 questionnaires distributed. These questionnaires were slightly amended in line with the comments above and with three additional questions designed to establish precisely how many schools had been considered and visited before the choice of school was made. (See Appendix B)

A 52% response rate was achieved with a further 12 parents agreeing to be interviewed. Analysis of this batch of questionnaires reinforced the tentative hypotheses emanating from the earlier batch. Similar patterns emerged, that is that it appeared to be mothers who provided care and that there seemed to be a disproportionate number of mothers classifying themselves as 'unemployed' or some other self category equivalent to not being in paid work

In total 58 questionnaires were circulated to parents via Ash and Beech. Of these, 32 were completed and returned with 23 parents also agreeing to be interviewed. It was felt that this size of sample would generate sufficient data on which to base a discussion of factors relating to parents choice of a special school.

The next phase in the research process was to be conducted using interviews and a discussion of this process will form the basis of the next section.

THE INTERVIEWS

Throughout this chapter emphasis has been placed on the need to employ a method which would enable the Northern parents' view of the world to be revealed. This, it is argued, is necessary if sense is to be made of their reasons for choosing special education for their disabled child. Questionnaires proved to be a useful tool for gaining background data but a method offering greater scope to explore parents views in depth would be necessary for the major part of the empirical work. Interviews were considered to be the most effective way of eliciting parents views and were, therefore, chosen. This section discusses the reasons for the choice and further develops the rationale behind the decision that the research would focus exclusively on the views of the Northern parents.

The reason that parents were chosen as the focus of the research has been discussed in several places above. However, because of the centrality of this decision to the research, it bears restating that the reason for deciding to concentrate exclusively on parents was taken because it is parents who take the prime responsibility for decisions concerning their children's future. This is the case for all their children, whether or not they have an impairment. However, this decision should not be taken as implying that it is only parents who make or influence decisions, or that children and other people should not be consulted and involved in the process. Rather it should be seen as following on from the criticisms voiced earlier, and returned to later, that parents shoulder a significant responsibility for the perpetuation of segregated education. Consequently, if reasons for a child's attendance at a special school are to be discovered then it is parents who will provide the answers to why they made the choice.

It is also acknowledged that research has shown that disabled children's experience of care and education is notable for the way in which their views are ignored, not documented, or that they have been denied a voice.

> 'Unfortunately, children in schools are frequently not treated as partners in the learning process and those with disabilities are sometimes patronised or excluded from dialogue.' Wade and Moore (1993:126)

It is pertinent to point out that children with impairments are more likely than their non disabled peers to be affected by legislation. Indeed, there is an anomaly for disabled children who come under the umbrella of legislation other than that governing education. As Morris (1998:70), has pointed out the Children Act 1989 requires children to be consulted and, specifically under Section 22 of the Act, also requires that there is a duty to both 'ascertain their wishes and feelings' and have regard to them.
So there are different expectations contained within legislation relating to education and that relating to social 'care'.

In clinical health settings the voice of the child is also given meagre recognition, as Strong found:

> 'Those who are of an age to take care of themselves are normally allowed considerable freedom to go their own way. By contrast, not only are children not granted this right, but even those who are formally responsible for them, their parents or guardians, now have to share that responsibility with the State and its agents. Modern children are, at least in part, public property.' (1979:202)

It is the last sentence that is likely to strike a chord in the lives of disabled children, and adults. Because of the amount of legislation which is often brought to bear in order to gain and maximise services. there is an inherent risk that disabled children become 'public property' in a way that all children do not. As such they are subjected to the opinions of others, thereby providing the opportunity for professionals to by-pass consultation with, or the involvement of, children. As John states:

> 'It may well mean that there is never a need for disabled people to be consulted as agents of social change because there are always 'experts ' to consult who can more effectively solve our problems!' (undated:4)

On this evidence the case is strong for the views of children to be researched. Notwithstanding, and bearing in mind Beresford's comment that:

> 'What these, and other research findings, demonstrate is not necessarily that adults are 'wrong', rather that they experience the same event or situation differently and are not capable of assuming the child's perspective.' (1997:7)

The issue of children's views forms a body of research and literature, for example, Beresford (1997), Minkes et al (1994), Morris (1998), and whilst its significance is recognised it was the above point that reinforced the decision to concentrate on parents. Namely, to include the views of children would be to include a different view of the world, nor would it provide answers to the research question. Furthermore, there appeared to be an absence of research on how parents themselves felt about making decisions on behalf of their disabled child. So, this issue became a significant feature of the research interviews by addressing the question of how parents felt about being expected to express their child's views as well as their own? That is, if they did, indeed, feel that they did. Additionally, the degree to which parents endeavoured to find out what their disabled child's wishes were when decisions about their future arose, were explored. As will be seen in later chapters, the responses to these issues proved to be illuminating.

Other factors also influenced the decision to focus on differing facets of the Northern parents' lives. These related to the limited amount of research on the role played by special schools in the lives of parents caring for a child with an impairment. Whilst, various pieces of research, Baldwin and Carlisle (1994), Beresford (1994a), Philp and Duckworth (1982(, Kagan et al (1998), have highlighted, the social and economic position of parents caring for a disabled child, across a range of issues affecting their lives, these have not been linked to the choice of a special school, nor have they been sufficiently developed to supply a reason for parents' choice of a special school. There is also research, Cameron (1997), Hall (1997), Haylock et al (1993), Read (1996), which has found that by virtue of attendance at a specialist centre parents receive a 'value added' level of support and information which would otherwise be unavailable. However, this work does not develop the links between the level of support and the role of mothers, but tends to take a broader sweep in relation to the overall level of information and services provided by specialist centres and the value placed on that by parents.

The above discussion provides an ethical and methodologically sustainable rationale for focusing on the views of the Northern parents. This being, that the evidence which would be produced, it was anticipated, would generate commonalties which would then provide a basis for developing theory on parents choice of special school.

Having established the rationale for focusing on the experiences of parents with a disabled child, consideration will now be given to the interview process.

THE INTERVIEW PROCESS

Although there are a number of data collection techniques available in qualitative research the interview is probably the most popular and most used. As Fielding states:

> 'Interviewing has a strong claim to being the most widely used method of research.' (1993:135)

One could safely put forward the view that this is because it is akin to human beings communicating at a face-to-face level. So it is with research. The researcher needs to find out things about people's experiences so the logic is that one asks questions. The format for this is the 'interview'. Interviews differ, however, from conversations inasmuch as they tend to be planned and structured around a particular topic. The degree to which interviews are structured can range from them being tightly structured around a fixed set of questions, to there being no structure, with the interviewee merely responding to an initial open topic linked prompt. Silverman differentiates between the two approaches thus:

> ' According to Interactionism, interviewees are viewed as experiencing subjects who actively construct their social worlds, the primary issue is to generate data which give an authentic insight into people's experiences; the main ways to achieve this are unstructured, open-ended interviews usually based upon prior, in-depth participant observation.' (1993:91)

The structured approach is characterised as being 'positivist':

> 'For positivists, interviews are essentially about ascertaining facts or beliefs out there in the world. While it is acknowledged that interviewers interact with their subjects, such interaction is strictly defined by the research protocol.' (1993:94)

The key difference epitomised by the two extremes is that the former sees the interview as an investigation, or an exploration, of a person's experience. The latter sees the interview as a method of collecting data to support or contradict a pre-defined hypothesis. Many researchers tend to operate somewhere between the two poles and opt for a 'semi-structured' approach. There is no precise definition of

what comprises a semi-structured interview so the degree of structure is up to the researcher to decide.

Flick (1998) identifies five forma of semi-structured interviews, The focused interview; The semi-standardised interview; The problem centred interview; The expert interview; and The ethnographic interview. It was decided that in order to elicit the information required to meet the objectives of the study the best format would be that provided by the focused interview. The use of this format would enable the interviewer to retain their focus on the main issues whilst allowing parents scope to expand on the their responses and to develop their thoughts. It was recognised that there was a risk that by using a focus format parents might unknowingly be limited by the scope of the questions. However, all the interviews would be conducted by the writer and it was felt that if parents appeared to be limiting their responses then there was scope within the format for prompts to be used to stimulate responses.

This last point, considered to be a strength within qualitative research, is also the subject of criticism, in that the process is considered to be too open to subjectivity on the part of the interviewer. This manifests itself in a variety of ways and includes the bias that the interviewer can place on both the asking of questions and the recording of responses, the dynamics between interviewer and interviewee will differ from one interview to another and, consequently relevance and correlation are prejudiced, the use of 'open questions', the criticism continues, will result in different responses from interviewees which creates problems for the reliability of the data because, as discussed above, unless there are common themes across respondents which, in turn, can be shown to link into existing literature, then the results risk being dismissed as a collection of individual anecdotes. Thereby precluding any possibility of grounding a theory in the findings.

However, notwithstanding the potential pitfalls, it was decided that interviews using a focused format containing a mixture of closed and open questions provided the most appropriate method for eliciting data.

Analysis of the questionnaires had determined the aspects which were to be explored in depth with parents, Accordingly a schedule comprising 26 questions was drawn up. It was decided that after the first three interviews the schedule would be reviewed.

The forms which respondents had completed and returned indicating their agreement to be interviewed contained the respondents address, the option to be contacted by telephone or letter had been given.

It had been decided to interview people in their homes and that interviews would be conducted at the time most suitable to the interviewees. This, it was anticipated, would ensure that the interviewee was at their most relaxed and were only minimally inconvenienced, thereby ensuring that the optimal conditions for positive and productive participation were achieved.

For convenience three respondents who had given telephone contact numbers were contacted and convenient interview times arranged. The three initial interviews consisted of two mothers and a mother and father together.

Some thought had been given to how best the responses could be recorded during the interviews. It was decided to tape-record all the interviews and whilst the difficulties associated with transcribing data of this type and the impact on the interview process itself were acknowledged it was, nevertheless, considered that tape recording would be the best method. Reasons for this were:

- The interviewer could concentrate fully on conducting the interview without the distraction of taking notes.
- It enabled the interviewer to keep the focus of the interview within the pre-determined parameters.

- The data could be maintained in its 'raw' state until full transcription and analysis had been completed, thus allowing the data to be accessed if conflicting themes began to emerge which had not been identified in the earlier transcripts.

- A purely pragmatic factor was that the researcher has a visual impairment so tape recording offered the most convenient method of recording.

The most negative elements associated with taped interviews are generally seen as being the time taken to transcribe the recordings and problems associated with codifying and organising the responses. Whilst the first of these is hard to challenge, transcription is time consuming. However, if the transcriber is the researcher, the person analysing the data, and is also writing the report, then it gives a further opportunity to reflect on the interviews in a calm and undisturbed environment. As Fielding points out:

> 'Transcription is undoubtedly tedious - it can take a day's typing by a competent typist to transcribe a one hour interview. But transcribing makes you very familiar with the data. It helps you to start making connections and identifying themes for analysis.' (1993:147)

The second point can be significant if unstructured interviews are recorded and underlines the advantage of pre-determining the parameters of the interview. So it was that the transcriptions were readily categorised and analysis facilitated by the advance planning of the interview content. It is worth noting at this point, that it was also planned to conduct a number of interviews by telephone in addition to those conducted on a face-to-face basis. However, as these were conducted towards the end of the series of interviews they will be discussed below.

One of the disadvantages of tape recording did manifest itself when some of the early interviews suffered from technical difficulties. This adds support to the view that one should always test the machinery and ensure it is working effectively before each interview.

It must not be assumed that either tape recorded interviews or their transcriptions are neutral and unaffected by extrinsic factors. The process of interviewing is intrinsically subjective throughout. From the selection of the questions, through the selection of interviewees, and finally the transcription of the recording. Unless an interview is to be transcribed and used in its entirety then there is an inevitable element of selectivity in the choice of what aspects to reproduce in a report. So, as Hammersley states:

> '...what are presented in ethnographic accounts are extracts from field notes or transcripts, and so we must bear in mind the process of selection at this level too, and the possible relevance of what is not quoted.' (1998:87)

That said, it is difficult to see how any research can be completely objective. All research, even 'pure' positivism begins with a choice of method which necessitates some degree of subjectivity so, what is perhaps more relevant is how openly the researcher acknowledges those aspects of the research and endeavours to declare and explore their relevance in relation to assessing the reliability of the research findings.

The initial interviews were conducted and reviewed. After discussion it was felt that there was a weakness in the interview schedule (See Appendix C) around the issues of young peoples autonomy and the role adopted by parents in relation to decisions concerning their son or daughter. Two further questions were therefore added to the schedule giving a total of 28 main questions. Although, as can be seen from the interview schedule in Appendix D, some questions also had sub-questions which were dependent on initial responses to some questions.

The schedule having been finalised the full interview process was embarked upon.

The initial interviews were conducted in January and February 1996. The full range of interviews were then conducted and completed by June of that year.

Interviews were arranged to suit the convenience of parents but as most of the interviewees were mothers it transpired that they invariably chose either mid-morning or mid-afternoon. This was clearly a reflection of the tasks they had to perform in relation to caring for their son or daughter and other home based responsibilities. Additionally, as the questionnaire data had highlighted, the majority were not in paid work so these periods during the day were the only time which mothers had the relative freedom to choose what they did. Some interviews were conducted during the evenings and these were with either the few interviewed mothers who worked or those who chose to be interviewed jointly with their partners. This also emerged as an advantage of telephone interviewing because mothers could choose whatever time suited them best due to the time not being constrained by either travel factors or family commitments. One example of this was a mother who chose to be interviewed at 8.30 in the evening. However, when she was contacted it was inconvenient so it was agreed to telephone again one hour later at which time she was able to relax and fully participate in the interview.

When the interviews with the parents of children at Ash and Beech were almost completed a preliminary evaluation of the data was conducted. The writer felt that whilst a picture was emerging about the experiences of parents with children under sixteen some of the issues around planning for the future and decision making were not adequately covered. This was because the ages of the children meant that the subject had not necessarily arisen. It was therefore decided to approach Oak College. There was, however, a notable difference between Oak College and Ash and Beech. This was that, although the principal of Oak agreed access she insisted that the letter accompanying the questionnaire and interview agreement form should be re-phrased so that it asked the students themselves if they would pass on the questionnaire to their parents. This created a minor difficulty because although the rights of the young people were not challenged the aim was to find out how parents felt and not their children. Nevertheless the questionnaires were rephrased and addressed to the students themselves (See Appendix E) and a further 36 questionnaires were circulated.

This raises a question in relation to the independence of the researcher to conduct research in the way that is considered to be the most appropriate to acquire relevant data. However, when negotiating access the power lies firmly with the gatekeeper, in this instance the college principal, so compromises may have to be made. In this instance the compromise did not alter the nature of the information elicited by the questionnaires although there were ramifications for the content of the returned questionnaires and, additionally, the returned forms specifying parents' willingness to be interviewed.

Of the 36 questionnaires distributed to students of the college 13 were completed and returned, a response rate of 36%. This was the lowest response of the three establishments by some 14 %. The number agreeing to be interviewed was 10 but of these it transpired that one had been completed by a young person and when the mother was contacted she knew nothing of it and declined to be interviewed. A further two had been completed by students living alone and did not therefore allow for contact to be made with parents. As a result the number of parents of students attending the college who were interviewed was reduced to seven.

Notwithstanding, the data yielded did ensure that the data accrued overall cut across a wide age range and, consequently, could be said to cover the age spread associated with primary, secondary and tertiary education, the age range being, in this instance, 5 to 22.

One can only hypothesise as to why the return rate at the college was lower but, given that the students themselves were likely to open the envelopes containing the questionnaires, it is possible that the students did not pass them on, or did not open them at all. A second factor could be that as the college is endeavouring to develop a greater level of autonomy in its students, the students acted independently and decided that they did not want their parents to be involved, Additionally, they may have reacted against what they might have perceived as adults acting in a way that they felt to be interfering in their lives and their right to choose.

All interviews were completed by June 1996. A total of 26 interviews had been completed and recorded on tape. But, as mentioned above, two had been affected by technical problems and were considered to be unfit for transcription. This raises the issue of the validity of any data that might be gleaned from the interviewers recollection of the content of those interviews. With that in mind it was decided not to try and paraphrase the interviews so that all the material used would be authentic and not tainted by overly subjective recollections and hindsight bias. However, it would be unrealistic to assume that the overall tenor of the interviews could be expunged from the interviewers thoughts, so it is fair to say that the themes which emerged from the undamaged transcriptions were not contradicted in the damaged tapes.

Transcribing the interview recordings was the next stage.

TRANSCRIBING THE TAPE RECORDINGS

All the tapes had been coded to preserve anonymity and indexed so they were readily accessible to facilitate transcription.

However, before the physical task of transcribing each tape was undertaken a decision had to be make on the degree of detail to be reproduced. Considerable debate has taken place on the validity and reliability of transcribed conversations and ethnographic interviews. The debate centres around how the transcripts are used. Positivists, for example, argue that interview data cannot be abridged or adulterated and must only be presented in its 'pure' form if it is to have any validity. Accordingly quantitative research requires particular measures to be taken:

> 'The reliability of interview schedules is a central question in quantitative methods textbooks. According to these books, it is very important that each respondent understands the questions in the same way and that answers can be coded without the possibility of uncertainty..' Silverman (1993:148)

Qualitative approaches differ in that transcriptions are data which requires interpretation. If patterns emerge over a range of interviews then this constitutes evidence. Subsequently extracts from transcripts may be used to support assertions although judgement needs to be exercised in how this is done. Silverman, referring to a review he had conducted of two social science journals, commented:

> 'I was struck by the 'anecdotal' quality of much of what I was reading. Much too frequently, the authors had fallen foul of two problems identified by Fielding and Fielding (1986)
>
> - a tendency to select field data to fit an ideal conception (preconception) of the phenomenon
>
> - a tendency to select field data which are conspicuous because they are exotic, at the expense of less dramatic (but possibly indicative) data.' (!993:153)

Silverman is placing himself somewhere between the positivist application of transcriptions and the school of ethnography which tends to use life histories and personal accounts to provide insights into human experiences. The latter would argue that it is not their aim to provide irrefutable evidence to support a hypothesis, human experiences are valid in themselves and it is precisely the concentration on 'quasi' scientific approaches to social explanations that have allowed the 'real' experience of, for example, racism experienced by black people in Britain, to be hidden. However, the point made by Silverman regarding the selection of 'exotic' material is well made, and the temptation to use extreme anecdotes at the expense of those which illustrate an emerging pattern, should be resisted. That said, if a comment is made that is both 'exotic' and yet supports the pattern of responses then its inclusion is surely valid.

Miller and Glassner provide the following in support of interpretative approaches:

> 'All we sociologists have are stories. Some come from other people, some from us, some from our interactions with others. What matters is to understand how and where the stories are produced, which sort of stories they are, and how we put them to honest and intelligent use in theorising about social life.' (1997:111)

That presents the researcher with a challenge: how to present a coherent and reliable account from which valid theories can be developed, whilst honestly reproducing the essence of the human experiences.
So:

> 'How detailed a transcription needs to be, and what does and does not need to be included, then are matters of judgement that depend on the purposes of the research.' Boulton and Hammersley (1998:286)

In answer to the question of whether to transcribe tape recordings verbatim or selectively, Fielding suggests that:

> 'Verbatim transcription offers the advantage that all possible analytic uses are allowed for.'
>
> But:
>
> 'The advice is that even if you plan to be selective with most of the interviews you should still transcribe the first few verbatim. These will help build your analysis and quite possibly reveal lines of analysis you had not thought of.' (1993:146)

One aspect of the interview process discussed by, for example Mason (1996), propounds the view that the verbal interchange which constitutes the tape recording is but one element of an interview. Hence, it is argued, full account is not taken of non-verbal elements or environmental factors. This was acknowledged but it was decided at the outset that these elements, although they could not be disassociated from the interviewers subjective views of the interviews, would have no attempt made to document them in any organised or structured way. This decision was made because it was concluded that whatever factors might be documented these would be so value laden as to not withstand critical examination.

So, when considering the mode of transcription a range of options were available:.

- Firstly the interview can be transcribe verbatim in its totality.
- Secondly the interview can be paraphrased with the objective of retaining the meaning without unnecessary vocabulary.

- Thirdly passages can be selected and transcribed verbatim so as to retain the meaning and the original context.

The first of these was rejected on the grounds of time. The second was also rejected on the grounds that it was too prone to manipulation by the researcher. Finally, the third approach was adopted.

The tapes were initially transcribed by the researcher who listened to passages of the tape recordings and then selected representative sections to transcribe verbatim. It is acknowledged that this leaves the results open to criticism on the grounds that the researcher was, inevitably, subjective in his selection of passages which may have been chosen on the grounds that they supported the hypothesis, rather than reflecting the true picture. This may be so but, as discussed above, so is the whole research process. It has to be recognised that the research process is not neutral and that bias, subjectivity and values all undermine notions of objectivity. This becomes a problem and diminishes the value of the research if it is not felt to be a factor and is therefore not acknowledged. However, this criticism was, to a degree, borne out when the tapes had to be fully transcribed by an audio typist because the original selective transcription contained insufficient material. This was not an issue of the relevance of the content but rather the quantity available to provide material to legitimise any conclusions which might subsequently be made.

Boulton and Hammersley (1996), referred to the exercise of 'judgement' when selecting from transcripts. But the exercise of judgement straddles all aspects of the research process and judgement carries with it an ethical dimension. It is the exercise of judgement in an ethical manner that will now be discussed.

ETHICAL CONSIDERATIONS

Arguably, one of the consequences of the growth in both social research and the teaching of research methods in universities is a recognition that research should be conducted ethically. However, when it comes to specifying what is ethical some problems arise. As a way around individualising ethical approaches, professional

bodies have adopted 'codes of practice' on how research should be conducted ethically. An example of this is the British Psychology Society's production of a document outlining its ethical approach titled: 'Ethical Principles for Conducting Research with Human Participants'. This code along with other such codes, and literature on the subject, have a similar set of core concepts as their foundation.

These tend to be:

- informed consent
- protection of privacy
- ensuring no harm is inflicted on participants. and
- the need for researchers to be honest about their intentions.

Homan (1991) offers some cautionary comments on the application of codes, particularly in social research. His view is that there are problems with adopting codes in areas where social research is carried out on five counts. Firstly, they 'have no teeth' so consequently they cannot be enforced. Secondly, adopting a code implies an aspiration to a 'final' adoption of the code. Thirdly, an aspiration to a final code assumes, somewhat spuriously, that there is, or can be, a professional consensus on what constitutes an absolute statement of ethical principles. Fourthly, codes 'enshrine' practices so that when a practitioner is caught on the horns of a dilemma relating to what is seen to be ethical in her/his mind, yet is not accommodated within the code, she/he will look for a loophole in the code. Finally, a code cannot cover every eventuality so, although they might provide guidance and control, they may be equally limiting in unique circumstances.

However, the research under discussion here was not subjected to any code of ethics, and looked for guidance to writers located predominantly within ethnographic approaches to research. Two such writers are Sapsford and Abbott who suggest that:

> 'Careful consideration needs to be given to the ways in which anyone whose interests are touched by the research might be harmed by it or by the dissemination of its conclusions.' (1996:317)

Commenting on ethnographic studies Hammersley identifies the following as being issues around which there has been debate:

> 'deception, privacy, damaging effects on the people studied, and consequences for future research.' (1998:138)

The four points are almost exactly the obverse of the core components identified as being present in most ethical codes. It would appear, then, that there is a broad degree of consensus as to what the researcher should exercise judgement on in relation to how research is conducted and data collected and reported.

For that reason each of these will be considered in relation to the study under discussion.

Firstly, informed consent. From the outset no direct contact was made with any of the participants until consent had been agreed. Initially the Acorn Society was approached before establishment heads were contacted. All parents received a letter (Appendix C) explaining the aim of the research and guaranteeing anonymity in the case of completed questionnaires unless the parents were willing to be interviewed, in which case the was an authorisation form for them to sign and return. Parents were always contacted prior to interviewing when the aim of the research was reiterated and an appointment made. Each interview was prefaced by a further explanation and a request to use a tape recorder.

It is acknowledged that the concept of informed consent is open to criticism, Homan (1991), for example, points out that informed consent is used as a protective cloak for researchers who feel that once 'informed consent' has been granted it gives them a licence to conduct any form of investigation they consider to be necessary to accrue data. It is in circumstances such as these when the only safeguard available is the belief that the researcher will exercise their judgement 'ethically' and not conduct any procedure for which the participants have not been fully informed and given their consent.

Secondly, participants privacy has been protected by:

- anonymous questionnaires,

- all references to individuals, establishments, geographical areas, and organisations are written in such a way that anonymity is preserved.

Thirdly, all contact with participants was conducted with sensitivity and endeavoured to ensure that any issues which might cause distress to interviewees were highlighted before the interview commenced with interviewees informed that if they felt at any time that questions were inappropriate they should not answer them. It is not anticipated that the data analysis and subsequent discussion will contain comments or recommendations that will in any way be harmful to individuals falling within the ambit of the research.

Finally, at all times and in all contact with participants, that is, parents, professionals and disabled young people, the researcher was frank and open about his aims in conducting the research and his personal motivation in undertaking it.

It is believed that by following the above procedures the research was conducted in as ethical a way as is practical. This may have the ring of a apology but it is a recognition that in the realm of human interaction in the 'real' world it would be foolhardy to presume that the impact of the researcher's actions did not, at some level, cause someone to feel anxiety or distress as a reaction to the interviews. Indeed in one interview, the interviewee was distressed to the extent that she shed tears. This was the only incident of overt distress and it was handled with delicacy and tact and, at the express wish of the interviewee, the interview was completed.

This incident does, however, raise a more general issue about the use of interviewers in research. This researcher is an experienced worker in the field of social service provision, and has experience of working in a number of settings with service users and other individuals. Consequently there was a strong element of communication skill which might not always be present in all researchers. Consequently, if ethical considerations are to be treated seriously then there is a need for those interviewing service users or other respondents, to be experienced and trained to deal competently and appropriately with people who exhibit emotional distress. Having made that point the chapter will now be concluded.

SUMMARY

The aim of this chapter was to discuss and analyse the research process and the rationale behind the choice to concentrate exclusively on the views, opinions, and experiences of the Northern parents..

This contained several components. Initially the parameters of the research were identified as being to ascertain the views of parents of children with impairments attending a special school on how and why they chose a special school for their child. Having articulated the initial objectives of the research it was then shown how information contained in the first set of returned questionnaires had prompted a re-appraisal of those objectives. The decision to concentrate on parents' experiences using a group of parents to be known as the 'Northern parents' was explored and the rationale behind the decision was detailed. The discussion proposed that by focusing on the Northern parents, a fuller and deeper understanding of parents experiences of caring for a disabled child would emerge. This in turn, it was hoped, would provide information which would enable hypotheses to be developed which might establish that there was some link between the demands of caring for a child with an impairment and attendance at a special school.

Following on from this, the process by which the study would be conducted was evaluated. Issues relating to the use of questionnaires, conducting interviews, transcribing data, and ethical considerations were covered. Contemporary issues in research were integrated with the discussion of the research process so that the research could be seen within a wider context of research and the process of researching social life.

The background for Chapter 3 has been set out. The primary source of empirical data will be drawn from interviews conducted with 26 parents of children with impairments attending special schools run by the Acorn Society. These will be known as the 'Northern parents' and comprised; twenty mothers, four mothers and fathers, and two fathers. All the parents were white with one exception [Pen

portraits of the Northern parents are provided below]. No claims are made that the sample is representative of any larger social group or movement but rather it is argued that the value lies in the detailed accounts of personal experiences that the interviews will elicit. It is those interviews which will be recounted and discussed in Chapter 3 But, Chapter 2 will provide an analysis of the survey data and information on the three educational establishments through which access was gained to parents.

The Northern Parents

The Northern parents, mostly mothers, but also couples and, in some instances, fathers generously gave their time. To maintain their anonymity it is only practical to give the briefest details of their background. However, the brief details provided below will gives some indication of family composition.

PARENTS OF CHILDREN AT BEECH SCHOOL (THE SECONDARY SCHOOL).

'ANDREW AND SUSAN' live with their two daughters, the eldest of whom has an impairment acquired following surgery. Sara has attended special schools since approximately age seven. Susan does not have a paid job, Andrew is a skilled manual worker.

'JANICE' lives with her husband and eight children. Janice is a qualified midwife but has been a full-time foster parent for her local authority social services department for over twenty years. Two of her children have impairments. One of her daughters, Jane, has multiple impairments and has always attended special schools.

'SHEILA' lives with her husband and three sons. James, the middle son has an impairment and has always attended special schools. Sheila categorises herself as a housewife.

'ALICE' lives with her husband and two daughters. Linda, the younger, has an impairment and has attended special schools since the age of three. Alice categorises herself as a housewife.

'FAY AND JAMES' have three daughters. The eldest is at University and the youngest two live at home with them. The youngest daughter, Louise, has an impairment and has always attended special schools. James is a non-conformist church minister and Fay categorises herself as a housewife.

'PAT' lives with her husband and their son and daughter who has an impairment. Gail has always had specialist provision. Pat works as a secondary school teacher.

'ANGELA' lives with her husband, two sons and their daughter. Alan, the elder son, has an impairment, He has had special provision and attended special schools since the age of eighteen months. Angela categorises herself as a professional and worked as a nurse until the birth of her eldest son, since which she has not had a paid job.

'HELEN' lives with her husband and two sons. The elder of whom, Alan, has an impairment and has attended special schools since the age of four.

'MOHAMMED' lives with his wife and their daughter and son, Jamil, who has an impairment. He started his education in a mainstream school at the age of five but following an operation at age six continued his education in special schools. Mohammed himself has an impairment and now categorises himself as unemployed although he has previously been in paid work.

'DENISE' lives with her husband and two sons. Thomas, the elder son has an impairment and has attended special schools since the age of two. Denise categorises herself as unemployed.

PARENTS OF CHILDREN AT THE ASH SCHOOL (FOR CHILDREN WITH AUTISM)

'DEBBIE' lives with her husband, daughter and son, Alec, who has an impairment and attends the school for children with autism. Debbie categorises herself as unemployed.

'JOHN' lives with his wife and two sons, the younger of whom, Edward, attends the school for children with autism. John categorises himself as a professional.

'ADELE' lives with her husband and has four children. The eldest daughter being 26 and the youngest, Tony, aged 12, has an impairment and attends the school for children with autism. Adele does not have a paid job.

'FIONA AND EDWARD' have two daughters and a son. The youngest daughter, Nicola, has an impairment and attends the school for children with autism. Fiona categorises herself as a housewife and Edward as a self-employed painter and decorator.

'ANNE' lives with her daughter and son who has an impairment. Henry attends the school for children with autism. Anne categorises herself as a computer operator who now cares full-time for her son.

'NICOLA' lives with her daughter and two sons, one of whom has an impairment and has attended special schools since nursery school. Nicola categorises herself as semi-skilled and is studying business at an institute for higher education.

'SOPHIE' lives with her husband, daughter and son who has an impairment. Kevin attends the school for children with autism. Sophie categorises herself as semi-skilled but is unemployed.

'LINDA' lives with her husband, daughter and son, Ian, who has an impairment and attends the school for children with autism. Linda categorises herself as a technical and administrative worker.

PARENTS OF CHILDREN ATTENDING OAK COLLEGE (THE POST-SIXTEEN COLLEGE)

'RUTH' lives with her husband, two daughters and son. One daughter, Helen, has an impairment and has received special educational provision since primary school. Ruth works as a residential care worker for a social services department.

'HELEN' lives with her husband, two sons and a daughter. Katie, the middle child, has attended special schools throughout her education.

'MARGARET' lives with her husband and two daughters, the elder, Hazel, has an impairment and has received all her schooling in special schools.

'SYLVIA' lives with her husband and daughter, Paula, who has an impairment. She has always attended special schools. Sylvia works with parents of disabled children.

'JANET AND DAVID' have three sons, the eldest, Simon, has an impairment and attended special schools since infancy. Janet is a part-time community nurse and David is a general practitioner.

'SANDRA' lives with her husband, two daughters and one son. One daughter, Shirley, has an impairment and has attended special schools since she was two years old. Sandra has a part-time semi-skilled job.

Chapter 2

The Survey Data

INTRODUCTION

Chapter 1 provided a detailed discussion of the research design used in surveying parents with a disabled child at one of the Acorn societies special schools and also how the experiences of the Northern parents would be elicited. This chapter will present the detailed analysis of the survey questionnaires which will provide a factual background by identifying characteristics in the lives of the Northern parents and their families, which will provide a greater sense of the circumstances of the Northern parents.

ANALYSIS OF THE QUESTIONNAIRE DATA

The questionnaires had been designed to provide information on the following:

1. The pupils and students attending each of the units in relation to:
   a Age
   b Sex
   c Previous School
   d Whether and age statemented

e Distance and time spent travelling to school.

f Mode of transport used.

g Nature of impairment.

h Need for personal care and assistance.

2. Parents in relation to:

a Time spent providing personal care and assistance for their child.

b Family composition.

c Parents occupation.

d If they had considered other schools, the number considered and the number visited.

e Value placed on advice given by different professionals.

f Reasons for choosing the particular establishment.

As mentioned earlier, analysis of the first questionnaires returned by parents of children at Ash school resulted in the research being re-focused. This was largely a reaction to responses to the open question, 2f, which asked 'Why did you choose Ash school?'. But, whilst that question provided qualitative information, the remainder of the questionnaire was designed to elicit data of a quantitative nature. If any similarities and differences between the Acorn survey and findings from other research became evident, then it was anticipated that there would be some limited potential to make comparisons with other research, for example, the OPCS Survey into Disability in Great Britain, Report 6, Disabled Children: services, transport and education (1989). However, the questionnaires were not designed with that intention, so any relationships are opportunistic, rather than intentional.

THE QUESTIONNAIRE DATA

Data was collected from each establishment and tabulated individually. A collective summary of all three was produced to give the study a quantitative background. However, as pointed out earlier, the interview sample was, to some extent, self-selecting. Accordingly, it was felt to be important to indicate how representative the interview sample was of the survey data as a whole. To do this numerical summaries of both the survey and the interview sample are presented in adjacent columns.

1. PUPILS/STUDENTS AGE

It can be seen that the overall age range covers that which can be said to represent the years during which children and young people would, potentially, be in full-time education. i.e. from primary at age 5 ,to completing a course of higher education at age 22. There were no differences between the case study and the interview sample.

	All questionnaires		Interview sample
Youngest	5		5
Oldest	22		22
Median	13.5		13.5
Mean Average	12.6		12.6

Table 1.1

2. PUPILS/STUDENTS SEX

There were more sons than daughters in the sample, the ratio of boys to girls being 5.5 to 4.4 in the total sample, and 5.7 to 4.3, for the interview sample (The Northern Parents). Meltzer et al (1989), and Gordon et al (2000) found that the OPCS survey conducted in 1985 identified the ratio of disabled boys

to girls as being three to two respectively. On that basis the study sample can be seen as having more girls in it than would be found in the population of disabled children as a whole.

	All questionnaires		Interview sample	
Female	20	44%	10	43%
Male	25	56%	13	57%

Table 2.1

3. WAS PREVIOUS SCHOOL SPECIAL

It was considered reasonable to assume that if a child's previous school or nursery had been a special one, then that might have some bearing on the parent's subsequent decision to select a special school. It was established that 80% of children featured in returned questionnaires had attended a special nursery, unit or school. The percentage was less in the interview sample, this being a reflection that proportionately more people were interviewed from the secondary school, where 69% of children had previously attended a special nursery or unit, than the college where 100% had previously attended a special school...

	All questionnaires		Interview sample	
Yes	36	80%	16	70%
No	6	13%	4	17%
No response	3	7%	3	13%

Table 3.1

4. WHETHER STATEMENTED

Parents may request an assessment of a child's educational needs under Section 173 of the Education Act 1993 (subsequently subsumed into the Education Act 1996. If an assessment establishes that a child has special educational needs then those needs are required to be set down under Section 168 in a 'Statement of Special

Educational Needs'. The significance of statements will be a feature of later discussions.

	All questionnaires		Interview sample	
Yes	42	93%	22	96%
No	2	5%	0	0
Not sure	1	2%	1	4%

Table 4.1

5. AGE WHEN STATEMENTED

The age at which a child was statemented was considered to be significant because it might provide information which could indicate if the age at which a child had been statemented had any significance in the process of choosing a special school. The questionnaires and the interview sample showed no difference in the age at which statementing took place The youngest being statemented at age 2 and the oldest at age 15. Whilst this does not identify how long children had been statemented it did point to a variation between the youngest and oldest age at which statementing had taken place. These differences were subsequently explored during the interview process and the significance of this difference will be discussed below..

	All questionnaires	Interview sample
Youngest	2	2
Oldest	15	15
Median	8.5	8.5
Mean Average	8	6.6
Not known	12	5

Table 5.1

6. DISTANCE TRAVELLED DAILY TO SCHOOL/COLLEGE

There was a wide difference in the distance travelled to school, with the longest journey being 35 miles and the shortest 0.5. There would be relevance in comparing travel distances with both non-disabled children and disabled children nationally but that data is not available. However, research by Kagan, Lewis and Heaton (1998), found that parents of disabled children attending a special school had difficulty co-ordinating their caring responsibilities because 'The special school system means that children often have to travel long distances.' (:40) It is worth noting that the longest journey was undertaken by a child attending Ash School, whose parents had chosen that particular school. Whether this constitutes a problem with the 'special school system', or the failure of local authorities to provide appropriate schooling in the child's locality, is a matter for debate.

	All questionnaires	Interview sample
Longest	35	35
Shortest	0.5	2
Median	17.75	18.5
Mean Average	8.3	9
No response	4	2

Table 6.1

7. TOTAL DAILY JOURNEY TIME

Some indication of the variation in travelling time experienced by disabled children attending a special school is demonstrated by the differences between the interview sample and the sample overall, with a difference of one and a half hours between the longest, and shortest journey times. Comparisons with children in mainstream schools, whether disabled or not, would be useful because it could then be seen if attending a special school results in differences in journey time. Economic status is a factor which can

affect the choice of school made by parents of non-disabled children. Parents in socio-economic groups I & II are likely to have a wider range of options open to them, if they have the capacity to pay fees at a private school. Attendance at a private school could result in a child spending longer travelling to school than children attending their local school. Making such a choice is considered worthwhile by those parents, so it is, arguably, unreasonable to level criticism at the special school 'system' which is, like its private counterparts in the 'non special' system. providing a service to meet the needs of particular children.

	All questionnaires	Interview sample
Longest	2.5 hrs	60 mins
Shortest	5 mins	30 mins
Median	1 hr 13 mins	45 mins
Mean Average	44 mins	42 mins
No response	1	1

Table 7.1

8. MODE OF TRANSPORT

Again, comparisons are not possible due to an absence of comparable data. However, although it is conjecture, it is not unreasonable to postulate that non-disabled children attending mainstream schools would be unlikely to use similar modes of transport in such proportions. Equally one could conjecture that disabled children in mainstream education are just as likely to use the modes of transport used by their disabled peers attending a special school, because public transport is equally inaccessible for them, and the physical practicalities of getting to their local school may be just as problematic.

	All questionnaires		Interview sample	
Taxi	14	31%	8	35%
Minibus -Hired)	27	60%	13	57%
Private Car	2	4%	2	9%
Public bus	1	2%	0	0
Walks	1	2%	0	0

Table 8.1

9. NATURE OF PUPILS/STUDENTS IMPAIRMENTS

It is acknowledged that isolating impairments by diagnosis is problematic and undermines the conceptualisation of disability as being socially determined. Focusing on the impairment itself reinforces the medicalisation of disability and individualises problems rather than concentrating on the social causes of disability. Attempts to 'measure' numbers of disabled people have been attempted periodically over the last half century. Examples of these are, the Harris survey into 'Handicapped and Impaired in Great Britain' published in 1971, Sainsbury's review: Measuring Disability (1973), and the OPCS 'Survey into Disability in Great Britain' published in 1989. Each of these endeavoured to measure degrees of impairment. In the case of Sainsbury and Harris this was defined as 'disability'. In the case of the OPCS survey the term 'impairment' was used to define levels of service use. Surveys designed at establishing how many disabled people there are in Britain have been criticised by the disability rights movement, notably Abberley (1992), for adopting an individual model based on arbitrary measurements of impairment formulated by non-disabled experts. Gordon et al (2000) in their 're-analysis' of the OPCS data on disabled children have commented that the criteria used by the OPCS meant that there estimates of numbers of disabled children in the population as a whole 'were at the lower end of the range' which suggested that their definition of what constituted childhood disability was 'fairly restrictive' (:13) However, it was nevertheless felt that there may be a link between types and degree of impairments and the choice of a special

school. Furthermore, it was felt that parents should not be limited in the way they chose to express the factors influencing their choice of special education, so It was decided to ask parents to describe their sons' or daughters' impairment and enable them to do it in the terms they were at ease with..

The OPCS survey chose an approach using a banding system, with bands ranging from 1 - 10. Case study pen pictures outlining types of impairments and behaviours were used to identify within which 'band' a child should be classified. The numbering of bands meant that severity of disability was greatest at 10. Thereafter, in the survey, children were identified in their use of services by band/category. The OPCS method of measurement and categorisation has been severely criticised by disability activists, notably Abberley (1992), Barnes (1991), and Oliver (1996), because it focuses on impairment and not the institutional factors which cause disability and, furthermore, all the criteria used to rate impairments focus on negative aspects which look at what the disabled person, or in the case of Report 6 the disabled child, cannot do and/or has difficulty doing. Further detailed discussion of the social model of disability will be a feature of Chapter 5. Notwithstanding, and with these criticisms in mind, it is evident that children attending the three establishments would have fallen into the higher categories of the OPCS survey, that is, probably 7 - 10.

Parents often described their child's impairment in more detail than the table is capable of demonstrating, but it was clear that the highest percentage of children, when added to those parents defined as having Aspergers Syndrome, Social and Communication Difficulties, or Moderate Learning Difficulty, were those with Autism. This is not surprising as Ash was established solely to provide a service for children with autism. The second largest group were described as having multiple impairments. With the third largest grouping being cerebral palsy, it is safe to conclude that children with autism, multiple impairments, or cerebral palsy form the major proportion of

children educated in special schools. This has similarities with the OPCS data which identified that of children in Category 9 - 10, age 5 - 9 years; 67% were educated in special schools or units, likewise with children age 10 - 15 the percentage was 85%. There was a difference for children age 2 - 4 where the percentage was lower at 57%. It is reasonable, therefore, to conclude that the more severe a child's impairment, and the older the child is, the more likely they are to be educated in a special school. This is further reinforced by the OPCS survey which established that for all disabilities in the three age groups the percentage increased from 16% age 2 - 4, 26% age 5 - 9, and 47% age 10 - 15. With reference to the total number of children in special schools, DfEE (1999) statistics identify the percentage of children in special schools as having decreased overall. However, Gordon et al (2000) also established that disabled children aged 10 - 15 were more likely to be educated in a special school and were disproportionately represented in communal establishments and also amongst children being 'looked after' by local authorities under the Children Act 1989. Abbott et al (2000) have also established that older disabled children are more likely to be 'looked after' in residential units, than younger disabled children. Factore offering an explanation for this will be discussed in Chapter 4. Notwithstanding, it may be surmised that it is probable, given the research findings, that those remaining in special education are most likely to be those with the impairments listed below.

	All questionnaires		Interview sample	
Autism	15	33%	6	26%
Aspergers Syndrome	2	4%	0	0
Moderate Learning Difficulty	3	7%	0	0
Social and Communication Disorder	1	2%	1	4%
Downs Syndrome	1	2%	0	0
Multiple Impairments	10	22%	7	30%
Scoliosis	1	2%	1	4%
Heart defect	1	2%	1	4%
Cerebral Palsy	7	16%	6	26%
Duchenes Muscular Dystrophy	1	2%	0	0
Deaf and hyperactive	1	2%	1	4%
Curvature of spine/moility	1	2%	0	0
Not specified	1	2%	0	0

Table 9.1

10. PERSONAL CARE and assistance NEEDS

Parents were asked if their child had personal care needs, with the objective of establishing how many parents considered that they provided personal care. The aim being to establish if the children of the Northern parents received personal care at home, which might be another element in the decision to choose a special school. Because the role performed by special schools forms a key component of the interview process, discussed in later chapters, comparisons will be drawn later. However, Table 10.1 shows that the overall sample and the interview sample were similar with 17% of children not receiving personal care and assistance.

	All questionnaires		Interview sample	
Yes	37	82%	19	83%
No	7	16%	3	13%
Not specified	1	2%	1	4%

Table 10.1

11. TIME SPENT BY PARENTS ON PERSONAL CARE

The responses in T11.1 clearly highlight differences in time spent on providing personal care. The range could hardly be wider, that is from 24 hours to 30 minutes, this being a graphic illustration of the practical impact caring for a disabled child can have on parents. How the care is separated along gender lines is explored in greater detail in subsequent chapters.

	All questionnaires	Interview sample
Most	24 hrs	24 Hrs
Least	30 mins	30 Mins
Median	13.45 mins	13.45 Hrs
Mean Average	6.18 mins	1 Hr 4 Mins

Table 11.1

12 FAMILY COMPOSITION

The OPCS survey identified that 25% of parents felt that having a disabled child placed stresses and strains on their marriage. This is also supported by research, for example, Baldwin and Gerard (1990), Baldwin and Glendinning (1982), Quine and Pahl (1985, 1991), which identified that there were higher levels of relationship breakdown between parents and partners caring for a disabled child, than in the general population. Gordon et al (2000) also highlighted that one-in-five disabled children live with one parent, although this is qualified by the assertion that the OPCS data illustrated that this did not necessarily mean that there was only one adult in the household. Thereby implying that lone parents may have support from another adult, for example an elder child living at home. Table 12.1 indicates that lone parent families were not a significant feature of this study, although some of the interview data discussed later does identify how caring for a disabled child can impact on relationships.

A characteristic of the study was that the average size of families was greater than the current national figure of 1.8 children. Over 90% of families in the case study containing two or more children.

	All questionnaires		Interview sample	
Both Parents	39	87%	24	100%
One Parent	4	9%	0	0
Living independently	1	2%	0	0
Adult placement	1	2%	0	0
Only Child	2	4%	2	9%
1 Sibling	19	42%	11	48%
2 Siblings	15	33%	7	30%
3 + Siblings	8	17%	3	13%
No response	1	2%	0	0

Table 12.1

13. PARENTS' OCCUPATIONS

Later discussions on the cost of caring for a disabled child, and the role of professionals in the lives of parents caring for a disabled child, will show that social status is a significant factor in parents' lives. At this stage in the process the objective of establishing parents' occupations was to find out if there might be a connection between socio-economic status, and the weight given to professional advice. However, it was not possible to make any such connection. However, it was evident that there was a high level of unemployment amongst mothers, this being 37%. One explanation for this is offered by Hirst (1992) who found that as disabled children grew older and entered their teenage years their mothers were less likely to return to work than were mothers of non disabled young people. The range of socio-economic classifications identified in Table 13.1 indicates a broad socio-economic mix. It is possible to argue that this is wider than might be found at a mainstream school which would tend to reflect the socio-economic balance of the schools catchment area. Given the responses to the questionnaire's open question it would perhaps be more appropriate to

identify parents on the basis of their ability to articulate and advocate. However, to do so would be problematic but an interesting comment in Gordon et al (2000) points to there being more middle-class parents with a disabled child than those from other classes because middle-class parents tend to have babies when they are older. So, because there is a correlation between the age of the mother and the incidence of impairment it is inevitable that there will be more middle-class parents with a disabled child. However, drawing conclusions from the information in this study is problematic, because the research did not explore issues of class any further than in the questionnaires and, whilst it was acknowledged that class and income are significant factors, it was considered to be of less relevance than parent's descriptions of their experiences. Additionally, it was felt that any attempt to place parents within a social class on the basis of the researcher's personal observations would render the data invalid and, furthermore, such an attempt would have breached the ethical position of the researcher in relation to his openness and honesty with interviewees. Nevertheless, the statistic on the unemployment level of mothers was considered to be significant and was a factor in the decision to alter the focus of the research, as discussed above.

	All questionnaires				Interview sample			
	Husb	Wife	Both	%	Husb	Wife	Both	%
Professional	10	3	15	17%	8	4	12	26%
Employer &/or Manager	5	2	7	8%	3	1	4	9%
Non-manual, Technical & Administrative	9	6	15	17%	4	1	5	11%
Skilled Manual	15	2	17	20%	4	1	5	11%
Semi-Skilled, Hotel, Catering etc.	1	4	5	6%	0	3	3	7%
Un-Skilled Manual	2	3	5	6%	1	2	3	7%
Unemployed	5	17	22	26%	4	9	13	28%
Self Definitions:								
Disabled	1	0	1	1%	1	0	1	2%
Sick	1	0	1	1%				
Housewife	0	2	2	2%	0	1	1	2%

Table 13.1

14. CONSIDERATION OF OTHER SCHOOLS AND VISITS

Choice was a central theme of the research. Consequently, parents were asked if they had considered other schools and, if so, if they had visited them.

Parents in the interview sample demonstrated that they had exercised more choice, 79% having considered other schools, than in the survey overall, in which this figure was 60%. Parents had then gone on to visit one or more schools, with the majority restricting this to two, one being the establishment subsequently chosen. The availability and exercise of choice is discussed in more detail in later chapters.

CONSIDERED OTHER SCHOOLS NUMBER CONSIDERED NUMBER VISITED

	All quest's		Int. sample	
Yes	15	60%	15	79%
No	10	40%	4	21%

All quest's		Int. sample
1	5	5
2	6	3
3	3	4
4	1	1

All quest's		Int. sample
1	2	2
2	7	6
3	6	3

Table 14.1

15. VALUE PLACED ON PROFESSIONAL ADVICE

As discussed earlier a key component of the research was initially to be the input of professionals into the process around choosing a special school, and the weight given to that advice by parents. Table 15.1 provides detail on this, and it can be seen that most weight is given to the advice of head teachers and the educational psychologist. It is pointed out later, that there are special factors concerning the category of educational psychologist because it was an educational psychologist employed by the local authority, within whose boundaries Ash School was located, who was due to become head teacher of Ash.

	All questionnaires						Interview sample					
	Most	A Lot	Some	A Little	All	%	Most	A	Some	A Little	All	%
Educational Psychologist	10	3	4	6	23	57%	5	1	3	3	12	52%
Head Teacher of												
Social Worker	1	2	1	0	4	9%	0	0	1	0	1	4%
Consultant	4	3	0	0	7	16%	2	1	0	0	3	13%
General	2	0	0	0	2	4%	2	0	0	0	2	9%
Parents of Pupils at Prospective	4	7	4	1	16	26%	2	2	1	1	6	26%
Head Teacher of Prospective	9	9	4	0	22	49%	6	3	2	0	11	48%
Physiotherapist	1	7	1	1	10	22%	1	3	0	1	5	22%
Occupational	0	0	0	0	0	0	0	0	0	0	0	0
Speech Therapist	2	1	3	0	6	13%	1	0	1	0	2	9%
Child	0	0	1	0	1	2%						
Own parents	0	0	1	0	1	2%						

Table 15.1

SUMMARY

The data generated by the questionnaires has provided a range of information on the background of the Northern parents and their children, and has offered some limited opportunity to place the study in a wider context.

Analysis of the data reveals that:

1. Children in the sample ranged from age 2 to 22 therefore giving access to a spectrum of parental experiences based on their child's stage in the educational process.

2. The vast majority of children had attended a special school prior to their existing one.

3. The percentage of children in the sample who had received a formal statement of special education needs, was 10 per cent greater than the national figure stated in the OPCS survey of 1985.

4. There was a spread of ages at which children had been statemented, this being 2 to 15.

5. Children travelled from 2 miles to 35 miles to get to school with journey times ranging from 5 minutes to 2 1/2 hours.

6. The majority of children used an LEA subsidised mini-bus to travel to school, this being 60%, with 4% making their way to school independently by public transport, or by walking.

7. If a child has autism or multiple impairments they are far more likely to be educated in a special school than those children with other impairments, despite falling numbers of children in special education.

8. 82% of the children in the sample had personal care needs, with parents stating that they spend from 30 minutes to 24 hours on those needs.

9. 87% of the responses identified that both parents lived at home and the number of children families was greater than the national average.

10. There was a high level of unemployment amongst mothers, and parents covered a wide socio-economic range.

11. 60% of parents in the survey had considered other schools, whilst the interview sample was greater, this being 79%.

12. The greatest value placed on advice given by professionals was attributed to educational psychologists, head-teachers and parents of disabled children at other schools.

Although some comparisons between the above research findings and national studies have been made, these should not be taken as an affirmation that the findings are statistically comparable with other studies. That there are similarities may be taken as some indication that the findings are not significantly different, but it does limit any attempt to draw statistical generalisations from the study.

That concludes the survey data received from the questionnaires.

Alongside the above, the nature of the sample from which the Northern parents were drawn was detailed by analysing the data accrued from the returned and completed questionnaires. Where comparisons could be made with existing research and surveys they were made but it was pointed out, and should be stressed, that such comparisons were limited in their scope and, therefore, any generalisations which might subsequently be made, would be of limited, if not, questionable, value.

This chapter has provided information on the circumstances of the Northern parents. This has placed them against a background of data giving some indication of their lives and provided scope for some preliminary discussions. The following chapter will show that, unlike the orderliness imposed by a structured questionnaire, the personal accounts of the Northern parents demonstrated that their lives contain more complexities than could be contained or accommodated by a questionnaire, no matter how complex the structure. The substance of this statement will be evident in the next chapter where the experiences of caring for a disabled child and the function performed by special schools will be developed at length and in some detail.

Chapter 3

The Study

Parents of Disabled Children: their experiences, feelings and views.

INTRODUCTION

Having discussed the means by which the Northern parents were accessed and the rationale for that process in Chapter 1, this chapter will present the views of the Northern parents, who comprised the 24 mothers and fathers with a disabled child attending a special school, elicited in a series of focused interviews.

Although the question of why parents choose a special school for their disabled child was the initiating factor, and continued as the prime objective throughout the research, it had become apparent from the first stage in the research process that an answer to the question was likely to be complex. Responses to the survey questionnaires had started to identify that a significant feature in the lives of parents caring for a disabled child was the level of personal care and assistance they provided for their child. Responses from parents relating to the time spent on care and assistance, such as "25 hours a day" from one mother, had caused the writer to reflect on how, when managing the resource centre, discussed in the introduction, it was noticeable that parents had been perceived as being disproportionately preoccupied with their daughter73 or son's care needs. This had been dismissed as a consequence of parents having been conditioned by professionals into medicalising their child's impairment. However, with the questionnaire data resurrecting this dormant perception it appeared, on

reflection, that perhaps it was not a 'disproportionate preoccupation' but did, in reality, reflect the part personal care occupied in the lives of parents. Could there possibly be, the question begged asking, a link between personal care and the choice of a special school? Furthermore, as the survey questionnaires had highlighted, mothers appeared to be meeting most of their disabled child's needs. This raised a further question, that being, could there be a more direct link between the choice of a special school and the fact that there was a gender difference in the care of disabled children? If an answer was to be found then the interviews would need to probe the relevant areas of parents' lives and ensure that parents were enabled to articulate aspects of family life, and the care of their children, which were significant to them.

Indeed, the views of the Northern parents did prove to be a rich and potent expression of their experiences and, to add evidence to the already expressed notion that parents caring for a disabled child lead lives of a greater complexity than do most parents, it was telling that parents did not necessarily express themselves strictly within the interview framework. Although the interviews were designed to follow a particular chronological path, that is from the time of a child being statemented as having special educational needs to adulthood, parents introduced topics and stressed key elements throughout the course of the interviewing process. Indeed, parents often spontaneously voiced disparate comments on varied aspects of their experiences in response to questions which were not intended to elicit those responses. Perhaps the most poignant illustration of this is the issue of disclosure. The interview schedule did not contain any question or direct reference to the way in which a child's impairment was disclosed to parents. Yet, there were very few parents who did not introduce the subject at some juncture during the course of an interview. Once it was realised that the interview prompts and questions were often acting as catalysts by provoking the thoughts of parents, then parents were encouraged to develop issues important to them which had not been included within the parameters of the interview schedule. This emphasised that far from parents seeing their, and

their children's lives within separate compartments, their lives were presented as a complex stew of care, school, hospital, support networks, relationships with professionals, managing households and other elements. So, if an answer to the question of why special schools were chosen was to be found then it was believed it would be by endeavouring to make sense of the complex interweaving of tasks, activities, thoughts and ideas. Notwithstanding the disconnected way in which many parents gave their responses, it was reasoned that the most accessible and logical way of presenting the Northern parents' responses would be to order them under headings. These, it was concluded, should follow a chronological path, taking as a starting point the recognition of their child's impairment, through their child's life, culminating with the present and their thoughts on the future. As will be seen, the result is a moving, yet coherent, insight into the experiences of the Northern parents which provided illuminating insights into the role special schools played in their lives.

The first part of the chapter will cover parent's views on aspects of caring and providing assistance for their disabled child. This will cover the issues of relationships with professionals, the costs of caring, the impact on family life, the consequences for mothers, parents as advocates, support from social services, parent's views on their child's future prospects, and parent's perception of their long term role in relation to providing support for their disabled child. The latter part of the chapter will then move on to cover issues relating to special education. These will be; the statementing process, the availability of choice when selecting a school, quality of support from special school staff, and issues relating to inclusion in mainstream education.

The chapter will conclude with a summary of the key issues and a discussion of the implications they have for parents who have chosen a special school for their disabled daughter or son.

So, the starting point is that time when parents first came to know that their child had an impairment.

THE EXPERIENCE OF 'DIAGNOSIS' AND ITS CONSEQUENCES

The term 'diagnosis' is used intentionally to emphasise the role played in the identification of an impairment by medical professionals, and to underpin the medicalisation of disability.

Diagnosing an impairment is fraught with hazards. On the one hand parents want a clear diagnosis of their child's condition, matched with a prognosis and explanation of what the future holds for them. On the other hand the emotional impact of learning that one's child has an impairment is immense. The medical profession finds itself in a difficult situation because doctors are often unwilling, or unable, to provide a precise diagnosis and even less able to give a detailed prognosis. However, that is to imply that the identification of an impairment takes place at, or around, the time of birth and is clearly visible. That can be the case for some babies but it is often parents themselves who feel that there is a problem with their child and have to press doctors for a diagnosis.

This was certainly the case with the Northern parents. Their experiences fell into three broad categories:

1. Those whose child had been born with an impairment which was clearly identifiable at birth.

2. Those who felt that their child's development was in some way 'different' to what they felt it should have been.

3. Those whose child for some reason had been having difficulties at school which required a medical diagnosis by way of explanation.

Although the different routes to a diagnosis required parents to adopt varying strategies the emotional impact at the time of diagnosis was felt strongly by all the parents. Both differences and similarities will be evident in the responses below.

Sandra had clear recollections of events at the time of her son Colin's diagnosis:

> "Oh, I can remember, I remember it all very clearly. I mean, it sort of left us in no doubt when he was born because he has so many specific deformities as well, and he also had a CAT scan which told us that he was brain damaged too."

For Sandra staff at the hospital had been understanding, supportive and clear in their approach.

> "They were very good actually. I had a doctor called Dr Smith at Firtree hospital and he was extremely good. He told us all along the line everything that was happening and what Colin's future, what he thought it would be. He was very good. The nurses were very helpful as well."

Fay's experience was somewhat different:

> "When Louise was born we were immediately put in a nearby side room, totally away from the other mothers and they immediately took you (nods in direction of her partner, James) to a quiet room to talk to you in isolation, and that was how it was dealt with. You realise that you are totally immediately separated."

> "At Louise's birth we were left in no doubt as to what Louise's future would be. We were told it was only days, that she wouldn't

survive the pre stage and I think we made the decision that if she survived the operations that we would have to take on this battle, this sort of challenge thing. At Louise's birth it was deplorable and they couldn't cope and maybe that was because my husband was chaplain at the hospital and I think they were absolutely devastated and I think they thought we are professional people, we should be able to cope. I think the fact that as we progressed in dealing with the situation we were transferred to another hospital, we were dealt with by new staff and new doctors. I think his point was there that there wasn't any sort of purpose, that we had two other children and ought to think ourselves lucky, and I think if we had been of any weaker nature we would have given up then, wouldn't we (looked towards James) but as I said, we made the decision that if she came through the operation then she was a real fighter, two days old and to go through what she did, and we thought she obviously had some strength to her."

Although Janet knew that her son had impairments she found clarity and information hard to come by:

"We were getting, certainly I was, the healthcare provision, you know, the latest they've ever written about depressed and obsessed about son's condition, our child to be, or not to be, and feel, you know, you want somebody to tell them what they think, what's their educated guess, what's his future going to be, what's your future going to be, and no, everybody's very wary, I mean, even being brutal and telling you that the darkest story can't be as bad as everybody saying 'oh, I don't know, let's just wait and see.' and a lot of talking going on in whispers behind your back, and the physio looked at the paediatrician and said I was upset and needed a break for a few days. We needed to be separated for a bit, I mean we were absolutely exhausted and he put him into

Peter house for a couple of days and gradually it was extended until he was there full-time."

Pat's experience was different; she became aware of her daughter's impairment gradually during the early years of her life:

> "No, we had no idea, it was really - instinct I suppose. I just felt that there was something wrong with Gail and having an older son, I know you don't compare children, but you can't really help it. I felt that she wasn't developing enough in the right way, whichever that was, and I went to my doctor and said 'she's making no attempt to crawl or anything'. I was told that that was OK, fine, and this'll happen eventually, everything seemed fine. She wasn't showing any - no sounds of distress."

At this point Pat had to adopt a more assertive manner and returned to her doctor:

> "I still wasn't happy so I went back to my GP and said 'look, I want her to see a specialist', so he says 'fine, if you can come up with a name I'll see what I can do'. So, I can't remember his name, heard about Northern children's hospital. So she went in for the day, had a series of tests and we went back for the results and we were told that her brain was very badly damaged. That she had cerebral palsy. I was totally unprepared for it. I had no idea what was going to happen and I felt that at that time I was not given any support. I suppose we were left to flounder around on our own and I do feel that if you are not fairly vocal you can almost slip through the net and not get the help you need."

Pat identifies an issue which proved to be a feature throughout the interviews, that is the need for parents to be 'vocal' if they needed a service.

Alice found it difficult to obtain a clear diagnosis.

> "Well, Linda when she was born, as far as we were aware, it was nothing wrong with her, she stopped breathing when she was three months old and after a lot of hospital visits, been in hospital and out of hospital every five minutes, she went to Firtree hospital and was diagnosed having cerebral palsy, only because at that time they were saying she was coming up to two and they kept saying she would need to go to, to go to a special school and I said 'well, until you can tell me what's wrong with her she is not going anywhere'. So it was really us pushing that got the diagnosis."

A consequence of these early experiences of the medical profession, and hospitals in particular, is that it affected parents' attitude towards professionals thereafter. Angela, talking of her son's impairments, recounted how during a feeding session conducted by a nurse her son stopped breathing, thereby preventing oxygen from getting to his brain:

> "That again was due to so called 'professionals'. I think generally, you know, we've got our list of horror stories just like anybody else has. It doesn't help anybody but you do get very hard when it comes to these people and you get tense every time you go into hospital. You are waiting for the next mistake, what is going to happen this time, you know. The surgeons generally, I mean, are not too bad but the thing is, if it goes wrong, it goes wrong doesn't it when he is in the hospital. It's not just a slight mistake that could be rectified, a big problem. It could change peoples lives."

To illustrate how criticism was not limited to the medical profession Alice spoke of how, throughout her daughter's life, social work professionals had appeared to be unable to comprehend what is involved in caring for a child with impairments. This has the consequence that there is a lack of appropriate support:

"She [social worker] has no idea of the pressures that we as parents live with every day of our lives, you know, hospital and everything else. You go to hospital expecting a normal hospital visit and you are told something which absolutely floors you, and every time, you never ever get used to that, it's as if you've been kicked in the stomach one more time, you never get used to that."

Angela's comments illustrate how early interactions with medical professionals had a lingering negative effect. Angela had developed a degree of scepticism towards the medical profession and provided further evidence for Alice's view that professionals, albeit in Alice's example, social workers, do not understand the emotional impact of both continuous caring and negative effects of intermittent set-backs in their child's life. Angela described a contact with a medical specialist, with ironic humour.

"I have come across some very strange people, so called professionals. I'll give you an example: Alan's testes did not come down when he was born and he got to about five and I was referred to a fellow in Firtree Children's Hospital, a surgeon. He did a laproscomy and said 'What we have here is a case of the vanishing testicle'. Now is that funny? I thought it was funny and I laughed. It sounds like a third rate detective novel. I thought it was hilarious. He looked at me and said 'It's not funny' I thought if that's not funny I don't know what is. It wasn't the condition I was laughing at, it was his calling it 'the vanishing testicle'. There have been a few occasions when people have said or done things that have upset me."

Most of the parents so far have been clear that their child had an impairment from birth or at a very early age and, whilst they tended to experience difficulties getting a specific diagnosis, they were in receipt of services. However, it will be seen that other parents had a different experience.

John told of his struggle to persuade professionals to recognise that his son had an impairment.

> "What happened was, everything was hunky dory 'til he was about two. I noticed that certain things he wasn't doing which he should be doing but he wasn't. I mentioned it to my wife and said 'Have you realised he's stopped speaking?' Stopped talking type of thing. Up to then everything was fine, like mummy and daddy, he was asking for what he wanted and then round about two everything petered out type of thing. It was like he went into his own little world. We weren't happy, so we went to the doctor's. He said 'Oh, it's nothing to worry about'. As they do. I said 'I'm not satisfied with that, I'd like a second opinion' and so he told me to go up to Firtree. So we went up there. They more of less said No.... there was something but they didn't know what it was. They wouldn't say type of thing. They just wouldn't do anything. Anyway, he went to nursery at three and the teachers there said there was definitely something wrong. He was very disruptive, wanted more attention than the other children, he wasn't speaking at all, he was in his own little world even more, climbed a lot, had no sense of danger, then he started doing little things like putting hands up to his head. As if there was a loud noise."

It would be some time before John's son was diagnosed and John's account will be returned to below.

Anne also experienced delays.

> "When I first got an idea that there was something wrong with Henry he was coming to second year stage, 'cause he wasn't playing with toys like normal children do and he used to pull this strange face and I didn't think. It wasn't particularly, it wasn't a happy face and I thought I'd ask the doctor and the doctor said 'Oh no.' and he didn't speak or anything but I still thought something

was wrong and I spoke to the doctors and they said no he will speak so I asked the health visitor if I could go to the child unit at Southern Hospital. It was a Dr Brown and I took him up myself, got there, sat with him half an hour and 'Henry's autistic'. It just came out that Henry was an autistic."

Following the diagnosis Anne commented on her partner's reaction:

"I don't think his father - he won't accept it and other people have said 'Oh no, it's nothing wrong with him'. He was obviously, you know, something wrong."

Adele spoke with passion about her experience. Again professionals are identified as lacking in understanding, in this case, teaching professionals:

"We moved here in the June, and he started school in September and he was four in August. They had this full time place and I thought 'Ooh, wonderful' you know. Anyway, he'd only been there three weeks and the teacher came up to me one night and said; 'Tony is either deaf or ignorant.' I said 'I beg your pardon?' and she says it again. I didn't know what to do with it so I took him to the Head Mistress and she said 'Oh, she doesn't mean that you know. what she said.'. Anyway, they got the nurse involved and then I got put in touch with the CDU, the Child Development Unit and he went along there and he saw eight different people and, lo and behold, he had eight different things wrong with him! You know, he had an ambling gait, and a devious squint .... and there was this little monster on paper. They insisted I keep him in school which would be better for Tony. It wasn't in that teacher's class but in the year above, 'cause that teacher couldn't cope. and we got to the stage where I would have to sit in school with him all day and in the end I said 'Oh no.' This is the educational psychologist's advice, keep him in school you know. So, in the end I withdrew him."

Finally, in this section, Andrew's daughter acquired her impairment following surgery which was traumatic for him and Susan.

> "Yes, in the way we sum it up with her, even if she is our daughter and everything. We want all to be great with the operation, we went down there with one daughter and came out with another one, she's got the same name, different person. I think if you were born with it or whatever, you just have to cope with it. But, all of a sudden, we were at the hospital for a few months, she come home, sat here, and I think she was in a wheelchair then, she is quite mobile now, but she was in a wheelchair then. We just sat here - like that - 'well what do we do?' Because that was the time when social services really fell down."

In this section parents have spoken of their experiences surrounding the diagnosis and identification of their son or daughter's impairment. With few exceptions they found the experience distressing with professionals either lacking in sensitivity, declining to provide specific diagnosis or discuss consequences, or ignoring parents remonstrations that their child's development was not proceeding at an appropriate rate. Parents' observations on their dealings with professionals catalogued a general dissatisfaction with their ability to communicate appropriately and their apparent inability to comprehend how caring for a child with an impairment had ongoing emotional ramifications. This theme recurred throughout parents accounts and will, consequently, continue to be a feature of this chapter.

Diagnosis has a major impact on parents and it would be difficult to underemphasise the strength of that impact. However, it is but the start of what is to become a qualitatively different experience of parenting to that of parents who do not care for a disabled child. The next section will, therefore, explore parents views on the effects having a disabled child have had on their lives, and the lives of others in the family, thereafter.

THE IMPACT OF IMPAIRMENT

Received wisdom would suggest that it is not only the child who is disabled but the whole family. Whilst this is something of a truism the accounts of the Northern parents would indicate that the experience of having a disabled child in the family does have a significant impact on the lives of all individuals within the family. However, care needs to be exercised so that the impact of disability on the child and particular individuals within the family, notably mothers, who provide the majority of care, is not diminished by being subsumed under conceptualisations of 'the disabled family'. Whilst proposing caution in the application of the disabled family concept, it is worth noting that because a child is disabled then they, and their families, are likely to have different experiences to most families. Those experiences will be unique and specific to all family members and will not only encompass events which arise as a consequence of disablement, but also those which happen during the routine of everyday life. The point being that everything which happens to a family with a disabled child, and all the activities and interactions they participate in, is not necessarily a consequence of, or affected by, having a disabled member of the family. Accounts of the Northern parents did highlight the impact having a disabled daughter, son, or sibling can have on many facets of family life, and the effect it can have on the ability of individuals to pursue activities outside the home.

Later in this section parents views on specific aspects will be featured but initially the following two extended accounts illustrate the breadth of the impact disability can have on families.

Firstly, Alice. A potential danger in selecting salient passages to supply comments relating directly to a particularly area of discussion is that the

impact of the total experience of the individual is lost in the cause of building a rigorous empirical case. This could be done with the following account Alice gave of the impact having a disabled daughter had had, on her life. In this account by Alice, and the subsequent one from Janet and David, the text of the interview is presented in a non-selective format. It is hoped that by stepping outside the standard format adopted in the rest of this chapter, the impact of the depth of Alice's undiluted feelings will be felt.

> "Well, I can't do anything. All I've got is a home. I have nothing else. Linda has asthma on top of everything else. She can go to school in the morning and by dinner time she is very poorly. You can have months when she is great and you can have no problems at all, but you can also have months and months were she is ill all the time and you don't get any break at all from it. I mean she has an inhaler for her asthma, she uses it all the time. She had an asthma attack - she's only had about four asthma attacks but everyone has been bad enough for her to go to hospital for. She has not been able to be treated at home, we had to take her in and she was having the inhaler she had had for years and she started having a cough which went on all last winter, right from September right through to April. She has this cough so she was in the hospital back and forth and it was because the inhaler that she was having, she wasn't getting it down the tube so we had to swap to another inhaler but it took, just to sort it out, six months and it was winter months. We were struggling all that time, school was saying she was coughing all the time, really bad asthmatic cough, and school was saying 'we don't want her in' and I was saying 'I'm not having her at home, I can't keep her off, month after month because she's got her cough'. The nurse was agreeing with me. She was sorting out the medication at school. The school didn't really want her in but she was barking like a dog. It was so bad but you had months and months where she was fine

and gives you a false sense of security really. Then you think it's going to be all right, everything is going to be fine - and then it all starts again.

But it does, it alters your whole way of life completely. You know, everything is, it sounds very hard but a lot of the parents tend to run here, there and everywhere with their children. Well, here it's Linda fits in with our way of life, we don't fit in with hers. It sounds very hard but to be forever running here, there and everywhere, taking her here and taking here there. I don't think it's fair on us. I don't think it's fair because a normal sixteen year old does that all on her own. She goes to a youth club on Friday, she goes, she did go out to a place called the Larches. It's a teenage services place, and they go out with a one-to-one person swimming or something. But the problem is you've got to take them there and well, she's supposed to be learning independence. That isn't learning to be independent because we're still doing the running about. Because my husband works twelve hour shifts he's not always here to take her. It makes it difficult but as far as my life goes everything, it's completely different. You sit in a chair, you see people going out in their cars for the evening and all this, well, that is a no-no as far as we're concerned because by half-past-eight she's ready for bed. She's sixteen but she doesn't have the stamina of a sixteen year old so by half-past eight she's dead on her feet. Because she's gone to the Willows [respite] tonight, she'll be later in bed tonight, come tomorrow when she comes home she's absolutely shattered because she's had one late night, she's on her knees. So as far as going out is concerned you've got to get somebody to look after her and people, well when she was small people accept the looking after but when they get to sixteen you can't really, it's very difficult because you see a sixteen year old girl but she still needs the same looking after as a three year old. So it's very difficult

really. I mean, we're going out on Saturday, it's our wedding night and we're taking her with us this time because I said she's getting older and we can't be forever looking around for people to have her and it's not fair to put the onus on Rachel [elder daughter] all the time because Rachel's got her life as well.

But it's the twenty-fifth one next year. We've never ever done it but we're going to go abroad on our own, not having any party or anything, just go out for a meal, the family, and we're going to book a holiday abroad on our own. Well that's what we're going to do so my mum and dad are going to come down and look after her while we go, you know so we'll have peace of mind 'cause they look after her like we do and it means that we can have a bit of time together on our own. But it's very difficult. It's like last week, we went, she was at the Willows like I say, and we sat here on the Tuesday trying to work out where to go because it's winter time and there's not really anywhere open - but I'll explode if I stay in when I had a day when I could go out and come back when I felt like - so we went to Sellafield, you know the exhibition centre.

Yeah, but it was just somewhere to go, but it was lovely to sit in the car and know that there's just the two of you and not have to be mithered. A lot of the parents tend to leave their kids at the Willows and go on holiday, I don't know how they get the funding but they do. They tend to leave them at the Willows and go on holiday but we've never ever done that. we've always gone away, where we've gone - she's gone.

You don't grumble and carry on and rant and rave, they just let you get on with it. But, the more noise you make, the more you get off them. But if, I've been told to cry and rant and rave, to cry on the 'phone and to cry in front of my social worker and tell the man how

much I need this, but it isn't really for me that I want it, It's that Linda's getting older. It's partly for me 'cause I want to know in my own mind that she can cope without me and the only way she's going to get that is by going to ask for it.

Oh, yes, I know this sounds really selfish but he [husband] can make arrangements to go out. He plays golf. He makes these arrangements to go out to golf with his mates and all the rest of it and he never ever has to sit back and think 'well, can I go?' because he knows that he can do everything he wants because I'm the one that's here with her ....."

Alice expresses strong feelings about a range of aspects related to caring for her daughter, Linda, and raises several issues about support and her ability to pursue her own interests. However, Alice speaks as a married mother so to compare Alice's account with that of an account given by a husband and wife together, Janet and David's recollections are also presented in their 'unabridged' form to convey the intensity of their feelings.

David "Where do you begin? How do you know? To be quite honest, I mean, there was one stage when I was thinking of going to, I had a plan to go for a job in Canada. Now I'm almost certain that I would never have got a visa, never be allowed to work in the country because of the problems of support. So I never replied, ah, I don't know, I mean I may have gone to Canada and hated it. You know, you just don't know where the alternatives would have led. I think as a family we've actually done very well. Got two other children who're fifteen and a half and fourteen, who're as well balanced as any fifteen and fourteen year old. They will fight with Simon, they have arguments with him, they will treat him as their brother and, really, I think they're remarkably good with him. There's no doubt that they miss out on certain things but having said that they're very caring, they're very loyal to him."

Janet. "Very caring of other people, very considerate of other people."

David. "Yeah, I don't think we do, as I said to you, you know, when we went to Florida for a fortnight we try not to let him limit us too much but what effect it has had on us and where we would be if Simon hadn't been like this I just don't know. I work full-time, Janet works part-time and has done full-time."

Janet. "I did it for six months because of my maternity. We managed it but I had to get childcare to meet Simon off the ambulance two nights a week whereas if Simon was eighteen he'd have been doing all that for me. I could perhaps be back full-time in a career. I might have gone further in my career. I don't know but then again I might not. I might have had six children, stayed at home forever more. The, oh sorry, I don't know what I thought, but it's gone completely. I think I'm over protective of the other two children because the worst disaster that could happen to me is if I had a child damaged. I mean Simon wasn't born with his disability he had a near miss cot death when he was three months old so Robert, my next child, wasn't, didn't sleep very much plus, because I was waking him up all the time, because it had happened to me once and I was, I mean, I don't think he slept for the first two years of his life. He was an always awake screaming baby basically because we were just so scared stiff. It shook us to the core and since we knew what happened to Simon in the first year of his life - 'was it going to happen again?' We were a bit calmer by the time Michael came along but I've just got this thing that every disaster that could happen is going to happen to my kids, so they'll tell you. They pat me on the head now, they're not streetwise kids because I've just kept them close to home all the time. I have ongoing nightmares of every scenario, you know, everytime a child snatcher, it's going to happen to my children. Because I was a

nurse who looked after people with loads of children I knew about cot deaths and all that sort of thing. It wasn't going to happen to me and it did. So, after, I just felt that everything was going to happen, so, they're kept pretty close. The school holidays are a bit of a nightmare because it's very difficult, I can't lift Simon on my own, the boys are actually getting bigger now and help me lift him but there were lots of times when we didn't go to places because the access wasn't good for the wheelchair or I didn't have the car or, you know, lots and lots of times we can't even go down to the meadows down the road because there's a stile to get in and you can't get the wheelchair over. Lots of things that people just take for granted. Or they wouldn't go on rides on a fair because I couldn't get the wheelchair on and I couldn't let them go on their own. So they would miss out on things, so we would avoid them."

David. "I think it's the emotional and physical strain that is considerably worse. The financial side of things, buying electric wheelchairs because they won't provide them and things like that obviously is something to consider."

Janet. "And you're penalised in that because we know people that are actually getting out of work so they can apply to charities and things to get electric wheelchairs and what have you. If you're on Social Security, if you're unemployed, I mean, we know people who have houses like palaces and they don't work. Because you can apply to charity for a grant for a little cripple child with a family that's quite bad and many of the charities means-test. Can you imagine if we applied to the trust for something? But we're working, but everybody spends up to their income and lives their life to their income, everybody does. I know very few people other than millionaires and I don't know any millionaires that have lots of free cash going. Whatever you earn you live to that, you pay a

mortgage or what have you. To go and spend three/four thousand pounds on an electric wheelchair. When Simon first collapsed we bought five push-chairs, 'didn't we?' because we couldn't find one that supported and kept him up. It never occurred to me that there might be somebody that could help us with it, nobody told us there was and we never, you know, I can actually remember seeing him as a baby, but we can't get him into the push-chair we had that was bought for us when he was born, doesn't suit him, there's nothing to support him, he can't sit up, 'what are we going to do?' Nothing was said and we had friends saying 'I've seen a pushchair that'll fit him' and it'd be fine in the shop and we'd buy it, and we'd get it home and the first time over a bump and he'd fall out of it. It was only when I started going 'I can't even take him out for a walk in the pushchair' and somebody said: 'Oh, you can get something from the NHS' and we were supplied with a very big thick pushchair that did actually fit. Retrospectively it didn't do his long-term back problems any good but at the time it meant I could take him out for a walk."

The accounts by Janet and David, and Alice have elements which featured in all the Northern parents' accounts of the impact of having and caring for a child with an impairment. Whilst there were variations specific to individual families, three elements were common to all accounts. These can be broadly identified as being:

1. The impact on siblings.

2. The impact on work and life opportunities, particularly for mothers.

3. The impact on general family life.

In addition a fourth aspect was evident in a number, but not all, accounts, namely:

4. The impact on relationships between parents.

Janet and David also highlighted the financial consequences of caring for a disabled child and whilst the literature also highlights this as a substantial issue it was not possible in this research to explore the specific financial circumstances of the parents who co-operated. That said, when parents have referred to financial consequences it has been included and in the remainder of this section the issues highlighted in 1, 2, 3, and 4 above, will be developed further.

IMPACT ON SIBLINGS

Parents spoke of their concerns that their non-disabled children did not get the amount of attention they were entitled to, or their activities were limited as a consequence of having a disabled sister or brother. Despite having concerns there was a sense of frustration borne out of the need to provide care for their disabled child, whilst striving to give the amount of time they felt was necessary to their other children. How real the disparity was is hard to quantify, it is possible that non-disabled children were getting a reasonable amount of time and that the concerns were over parity, rather than what a reasonable amount of time would be. Notwithstanding, the concerns were real for parents, particularly mothers, so the impact on parents was clearly felt.

Denise. "It's had a lot of impact on William, worrying. William's not quite two years younger but he's had to be older 'cause he has to act like the older child. He's had to be protective. We try to get Thomas into things like Scouts and Beavers, and William went as well, but he's been held back a bit because he has to be protective of Thomas."

Nicola. "Well, it's like the eldest lad, he [disabled brother] has language problems, and if his friends come round they can see that John acts differently and sometimes I think it puts people off a bit. There's some things we can't go to like other families, because of John. There's certain places I wouldn't take him."

Sandra. "Yeah, I mean it just changes your whole life and the brothers and sisters, you know, you can't say that they're kept apart from it, you know. As much as you try to be fair and equal with them all, it does affect them. When Colin was younger it was more difficult for the others then because he'd had so many medical problems, going in and out of hospital, and I have to rely on other people to pick them up from school, look after them, and it was really difficult because they were young themselves, the others may have needed me too and I couldn't be there. So ..... and you go on a big guilt trip then. So it makes it very awkward, just a family day out to different places, you know, you can't do all the same things because obviously there's certain things that a handicapped child can't do. And then on a social basis, because of the way he looks and the way he acts, then they get it from people staring at him and people calling him names and things like that. So I would say that it does affect them, but it could be a plus because it tends to make them more caring and more understanding of other people's needs."

The last point relating to the way in which non-disabled siblings developed positive social attitudes as a result of having a disabled sibling featured strongly in other accounts.

Janice. "So, yes, I think it does, just the fact that we all can't get out as a family for one thing, but I think it's very enriching because Jane's here and they are not afraid of people in a wheelchair and people with handicap, that it is just a matter of course and they tend, if

anything, to treat handicapped people just as normal. One of mine said something very rude to somebody at school who was handicapped and they thought that was the best thing since sliced bread, it was something about walking with crutches, but this kid thought it was great and said 'I wish more people wouldn't be so, trying not to say this, and not to say so and so', and my lad said it as a joke because we are used to that, we joke with Jane and you've got to be like that. So they tend to think that people with handicaps are just people, which is quite nice, a lot of people see the wheelchair first and the person second, so they are not frightened of people with handicap. They are not frightened with speech difficulties and I think in that way it is lovely because they are much better people for it but I think as a parent you've got to be constantly aware and that's quite a strain, you've got to be there for them, all of them, each and every child as an individual."

Angela. "..... my time is taken up with Alan which means I'm not available for them as much as perhaps I would like to be. They are aware of disabilities because they live with them all the time, they know, instinctively almost, what is needed. I found them learning especially by watching them. That is quite a positive thing, it has enabled them to get a grasp of what care is, which is good. There have been a few negative things like if you have been in town people stare. It does happen that at some point they are aware of what's going on. I remember Bev [sister] being very angry when she realised that people were staring 'why are they staring at him?', she goes, and I say 'don't worry about it, I don't know, maybe he's handsome'. But she is incredibly proud of him and she's a bit older."

Fay. "I think it makes the other two very defensive of Louise because, I think, they plead her cause very much when she is out. .....we do

have occasions when the girls have sensed that people stood and stared, 'you know she won't bite, she is house trained'. They come out with quips like that and they decided the best way is to embarrass people because they got so fed up that people make physical judgements.....our eldest daughter, only recently, grabbed some one and said 'just a minute, your lucky that your legs are running'. .....but they won't speak for her, they make Louise make her own decisions, they are very adamant about that, particularly towards the other relatives who talk down, or make decisions for her, they will say 'no she can decide that herself' and I think that's good."

Sophie pointed to an unforeseen, and unpredicted consequence that growing up alongside a disabled sibling had had on her non-disabled daughter.

Sophie. "When my daughter was a little girl, she will be five next month, something struck me when, he was three and a half when she was born and she can't notice any difference, and when I started taking her to play school she was shocked when children spoke to her. It was because she was not verbal and she would run to me if a child spoke to her, she would run away and come to me. Adults could speak to her and she could speak to adults, but she had difficulties with other children, and playing with other children, because at home when she was a baby and in a baby walker she followed Kevin everywhere and he just walked away, or pushed her away, because they are just two children. If a friend came with their children into the house she was frightened, she would back off and come to me and when I started play school she was more withdrawn, she was playing on her own and if a child came over she would drop the toy and walk away. The same as what Kevin would do to her, but he is chatting now. When she went to nursery they said she was so quiet and that she didn't interact as well as she should be doing with other children ....they felt that she was

> normal, they think she was all right but she was quiet and shy and that has carried on in school ..... the teacher called us in and said we were a bit worried about the social interaction, she is very quiet and she doesn't speak in a group and she doesn't really play with the other children as well as she should be, and that shocked. I mean we didn't realise it affected her, 'cause she is a chatterbox to us, but when she is on her own and away from us, the teacher actually said that my daughter was in a 'world of her own', and that was a terrible shock, and I thought she is nearly five and we sort of thought he hadn't affected her that much, but then we realised it had affected her and that was worrying.'"

It is evident that the impact on siblings is felt by their parents to have an effect on how their social attitudes and interpersonal behaviour develop. Some mention has also been made of the effect on the relationship between the parents of a disabled child, inasmuch as some of the Northern parents highlighted that the emotional reaction to learning of a child's impairment impacted on how parents subsequently related to one another. Notwithstanding, whatever happens within a family, at the level of individuals, and at the level of the family group, caring for a disabled child impacts far more on the life of mothers than other family members. This forms the focus for the next section.

PERSONAL OBJECTIVES

Parents were asked to develop their views on how having a disabled child had impacted on their ability to pursue personal objectives. Whilst this was intended to relate to personal achievements in the wider sense of education, leisure, voluntary work and other potential activities, parents tended to respond in terms of their professional development and their capacity to undertake paid work.

Indeed, the area of work and personal objectives was one in which gender differences were clearly etched. It was noticeable that, with few exceptions, mothers had felt unable to undertake paid work and that, as a consequence, their experiences differed from those of mothers with a non-disabled child of a comparable age. The following accounts will demonstrate this.

Angela commences with a stark, but telling, commentary:

> "Yes, my life has been put on hold really, and I don't know how long its going to last. Yes, there is a lot of things that I would like to have done that I couldn't. The first six or seven years of his life I was on my own anyway because his dad wasn't around any more. It would have been lovely to go out and work, to make my own way and all - independence. I couldn't see how I could work and still be the kind of mum that Alan needed, who could I leave him with? And that way I sort of thought, there is nothing I can do. I've got to be a mum first to Alan. So it just stresses me out every time I try to get back to work. I used to be a nurse, just devoted to him really, and that was it."

Sophie. "I'm not, I won't say I'm resentful though. I know people are very resentful. I remember feeling that my life is sort of ended now, in a way, my own personal life, like what I thought I was going to do with my life. I always wanted to be a nurse, people that go back to nursing. I remember thinking I'll do that when the kids are older and stuff. It was one thing I wanted to do, I was just trying to, you know, have a good career or something. That's that part of Kevin but I shouldn't assume that I'm not going to do that, but it's unrealistic, it's likely that he will be like that all his life."

Pat works as a teacher but believed that her career would have progressed further had she not felt the responsibility of caring for Gail.

"I think I used to be reasonably ambitious. I did give up work because of my children. I didn't just take six months off because they were more important. I should have time with them at home so I had about four years off and went back to teaching part-time and I think, really, I would perhaps have gone for head of department a lot earlier. I mean, I'm second in the department but I'll not go any further because I find it hard enough as it is and if I did that then I just would not have the time to spend with them. It really wouldn't be fair so that's a sort of selfish thing any way. But I think it has cramped my personal career, so to speak. I'm lucky to have a job, and lucky to have a good job, so I'm not complaining but I think it has definitely had an impact."

Sylvia also commented on feeling that her obligation to care had prevented her from taking full-time work.

"It stopped me sort of taking up full-time employment or it has done until the last couple of years when I decided that I wasn't going to hang around any longer. Like usually, when children are ten or eleven, you start to think to go back to full-time job, Or you may even go when they are five and put them in child care or whatever, but with someone with disability you tend to, you feel that you are the best person to stay at home and look after them. Also you can't really afford it if you are really working full-time, you can't really afford to pay someone, a carer, can't afford to pay the cost of having them look after them really. So it definitely impacted on anything I ever wanted to do."

Denise had made a brief return to work but it proved to be too difficult.

"..... I did go back to work for a year, just a little part-time job, and it was because of Thomas that I had to give it up because, like I say, the appointments to see him would come in a cluster and that's

why I gave it up really. I mean, I'm quite happy. I'm not bothered about not being able to work but it's the fact that you can't. I mean I would like to have further education at some point but....."

Debbie wanted to have a paid job but felt unable to do so. Consequently she looked to other avenues.

"I mean, lots of mums in this position are getting children to school and picking them up but, because of the nature of Edward and his disability, I couldn't be consistent to an employer. If he had a really bad day I can't be picking the phone up every five minutes and say to an employer 'I can't come in today, I'm having a bad day with my child.' Apart from 'where would you be if Edward hadn't developed autism' I have no doubt whatsoever that once I'd got those children at school I would have looked at some form of part-time job because I'm not that sort that just sits at home. I just have to be doing and I can't do because of Edward and lot's of it is his fault. I can still manage to juggle things within my life, which basically just brings out the strain of my life. What I have decided is I've got to look at it more positively, to help Edward. I'm fund raising at school so I contact people and generally try to fund raise for the school. Yes, I try to structure myself, to fill my days in other ways so I don't dwell on the fact of what I could be, that I actually was bringing money into the house to help the family income. But to set against that is the fact that I am also paid my benefit. If I do have a paid job I will lose my benefits, so it's a vicious circle, so I just have to busy myself."

This section has begun to identify a distinct characteristic in the responses of the Northern parents. Namely, that it was mothers who bore the brunt of the demands faced by a family caring for a disabled child. It was also evident that mothers were keenly aware of how this touched a number of spheres of family life. The wider impact on families will form the substance of the next section.

WIDER IMPACT ON FAMILY LIFE

The main issue highlighted by the Northern parents was the need to plan ahead and the problems that this, in turn, created. This could be separated into two elements. Firstly, any activity had to be planned well in advance, thereby restricting the capacity for spontaneous activities. Secondly, despite advance planning events all too often overtook them with the result that plans had to be abandoned. One consequence was that parents often chose not to plan at all and opted for the line of least resistance by staying at home. Sylvia's sentiments clearly highlight how this manifested itself for her:

> "Yes, definitely, they've sort of fences around her, you know, everything you do is centred around her. Will it be OK? Can we do it? Everything really, yes, it has a big impact. We have to drop everything and make her the number one and if we want to do anything we have to consider what she is doing first and you can't just think we can go out here. We have to think, 'can we get in?' 'Will it be suitable when we get in there?' 'Can we park nearby?' All that sort of thing. It does have a quite big impact."

Debbie. "Totally, absolutely, I mean such as this morning. Elaine [sister], I had to ring her school from nine o'clock to say 'we're having major problems with Edward, she is coming to school but she is going to be late'. She is already very upset because she thinks that she is going to be shouted at when she gets to school. Simple little things like this. Social life is practically non-existent for us as parents because the baby-sitters are limited as to who you can have and who can cope. So basically we've got two people, my parents, Eric's [husband] elder daughter, but my parents are

getting on with their age and Eric's elder daughter will soon be getting married. So what happens then?"

Helen. "It's very hard to plan things in advance. It's been difficult over the last few years. Back problems, we've been waiting for quite a while for her to go back into hospital for some other operations as well. So we can't plan ahead because we're always waiting for that hospital appointment."

Helen. "First of all you have a completely different life to that of your friends. They take their children to a range of places and holidays not suitable for us. In the early days when my friends had babies it was fine, we all went to the same parties and there was very little difference. As time's gone on it really doesn't work. Generally now it just doesn't work, they are leaps and bounds ahead of David So it's all those kind of things. It's the whole scheme of things."

The views expressed here by mothers point to their feelings of separateness, difference, and isolation; without any expressions of optimism that there was a chance of any improvements to their circumstances. The types of support which the Northern parents were receiving will be the subject of the next section. But, before moving on a return will be made to a topic briefly touched upon earlier.

Some parents commented on how they felt learning of a child's impairment and, subsequently, caring for a disabled child had affected their relationship with their partner. Whilst these were not large in number they do point to issues raised in other literature.

IMPACT ON RELATIONSHIPS

Themes emerging from parents' reflections on relationships centred around the impact that learning of a child's impairment had had on husbands and how they, mothers, had felt the need to react in a manner which supplied the emotional needs of their partner. The second strand was the strain caring for a disabled child placed on relationships.

Pat's comments on how she felt the consequences of having and caring for Gail had had on herself and both her marriage to Gail's father, and her subsequent relationship with her partner, illustrate a range of emotional ramifications:

> "Oh, yes, I think for a long time my, I went through the guilt thing you know, it's not a genetic problem, but you go back over everything - what happened, when do you pick up a virus style of thing which affected Gail and me at birth - or anything like that. This is what I've been told anyway. 'What could I have done?'. 'How could it have happened?'. You go through all this, and I do get very, no, I get very tired. I find it physically quite demanding, and she's incontinent at night, and she's not very good at looking after herself, she's not very good at looking after herself. She's almost constantly, she wants to be with you all the time, she's not good at entertaining herself, she's a constant presence and, obviously, things you might want to do might be curtailed, although we go abroad a reasonable amount and Gail always comes, when we go she goes, basically. And that's how I think it should be. I don't think we should mollycoddle her too much, I think I've been too gentle with her, but she can take all sorts of things really. Going to all sorts of different places, and I think it put a very great strain on my marriage. I mean, it's perhaps a small part but it is still a part of the reason why my marriage broke up. I think I found it harder to come to terms with than my husband but I may be wrong, you know, I don't know. I think I was more vocal about it.

Cry more you know. It's also very difficult in the present since I've remarried, she hasn't had a man in her life for a while, he comes along and it puts strain on the relationship now really. We've spent time together, Gail's always there, you know, and it is hard but you just have to get on with it really."

John. "At first it was very hard, it nearly broke me and my wife up. Definitely. When things were really bad, especially when we were going through the educational part we were under a lot of pressure. I was under a lot of pressure at work as well. I think everything got on top of each other and obviously that's when things started happening. Plus Edward was a handful then, he's calmed down a hell of a lot now, but it was hard work. But, I dunno, we didn't tell the parent of Brian who'd come here to ask how we'd coped, that you've just got to take each day as it comes. If things start getting on top of you then the best thing that I usually find is to send Edward up to his room, shut the door, and go downstairs and just relax. It's made us a lot stronger."

Sophie. "I say to people 'I worry about how I am going to cope when he's older' and they say 'well you'll have your daughter to help' and I feel awful. I think that's terrible and I think, no way am I going to expect my daughter to take on this. I don't want her to feel that as he grows up expecting to take over. I've stayed in this marriage longer when I don't want to because of Kevin because people say 'you are going to need, nobody else will put up with him, surely only the father could cope with the way he is'. I am not very happy and I've felt I wouldn't be able to cope on my own so I am a bit trapped really. That's not very nice although I have managed to do something about that now."

Angela. "Alan's dad was desperately, he was rocked by the whole situation with Alan, he just couldn't handle it. I think if someone had been around for him maybe things would have turned out differently. because he was the kind of fellow who thought he had to be strong, macho for me, and because I was so wound up with Alan, we were at the hospital every day for different appointments, physios and everything, that I probably didn't see it. I know there are many marriages that crumble under the pressure of a disabled kid, poorly kid, sick kid, I think that kind of compounds the tragedy and makes it twice as bad or even three times as bad as it needs to have been in the first place.

Everybody said to me 'watch your husband, a lot of marriages break down, you know.' But nobody said 'can we help', 'is there anything we can do?' If somebody had actually said to me at that point 'if we were to set up some type of counselling for you to see you through these first years' maybe things would have been different."

This section demonstrated that having and caring for a disabled child can have far reaching implications for the lives of carers and their families, and, potentially, for personal relationships. The implications can be seen to affect the development of siblings, the capacity to plan and execute family activities, and scope to develop careers and opportunities for paid work.

Angela concluded her comments with her opinion on what kind of service might have helped her. Indeed, the issue of support from statutory agencies is a significant one. Statutory agencies, that is, health, social services, and education, all have statutory duties to provide certain services. However, the degree to which services are provided is variable and so Angela's comment provides an appropriate link to the next section which will probe parents' views on the support they have received from statutory agencies and draw together the key issues they identify.

SUPPORT FOR MOTHERS AND FAMILIES CARING FOR A DISABLED CHILD

Previous sections have demonstrated that caring for a disabled daughter or son has predominantly been performed by mothers. This has been shown to have impacted on the capacity for mothers to pursue opportunities outside the home. It is, therefore, reasonable to assume that social service departments would be involved with families in developing support mechanisms and programmes to aid mothers, in particular, to care for their disabled child. Indeed there is a 'basket' of legislation relevant to parents caring for a disabled child at home. The Children Act 1989 places a duty on social services to provide for 'Children in Need', the National Health Service and Community Care Act 1990 and the Carers (Recognition and Services) Act 1995, empower local authorities to assess the needs of carers, whilst the Chronically Sick and Disabled Persons Act 1970, empowers local authorities to provide services for disabled children and adults. Consequently, given the need for support and given the legislative power to provide it, the assumption made above that it is 'reasonable to assume' that local authorities would, indeed, be closely involved with families and their disabled child.

However, the experience of parents did not indicate that this was uniformly the situation. Experience of social service departments varied considerably and this will be demonstrated in the following accounts.

Pat recollected that contact with her social services department had required action on both her part and by a teaching professional.

> "Yes, that's a bit of a sore point. When my husband left me, about three years ago, I decided I needed to contact ShareCare to get some sort of help because, you know, full-time job, two children.

My son was devastated, Gail didn't really know what was going on but she, in her own way, was suffering, myself as well, and trying to keep the house going. I felt I needed some support so I did contact ShareCare, got onto the waiting list and eventually, after about eighteen months, they managed to find me a family. I was told by the family liaison worker at the school that Gail ought to have a social worker because I suppose it's putting a pointer up to the community, they ought to know who is coming up into, you know, needing help.

Right, well, she wrote and said that this child 'blah, blah' and I wrote because she said I ought to have a family planning meeting. I had a letter back saying 'blah, blah' they were unable to give me a social worker at this time. I was very unhappy about this and when I went to see Norma [head teacher at Beech school] to have the meeting. I told her about this and she said that this is absolutely ridiculous, Gail is thirteen, they need to know she's coming up into the system so they can make provisions. She wrote to social services .... Within a week I had a letter back saying 'I am your social worker'. So I thought, this is ridiculous, I was just being fobbed off and I now have a social worker. She's only come twice, she's, it's an initial stage and she's meeting Gail, she's met me and she's going to come again and, I think, with a view to having a planning meeting and try and map out Gail's future, but that has only just happened."

Fay and James recalled similar difficulties:

Fay. "Yes, this is the one frustration, we find the social services very slow and haphazard and I think maybe the sort of work we are having done, at this moment in time we are waiting for adaptations to our house, they have now decided to put in a wheelchair ramp."

James. "But we did approach them before we even moved to the area because we had all the hassle about - would they accept costing of the equipment by another authority and they knew what to expect. They had Louise's profile and everything, and we also met with them before we moved into the house here, so we could then prepare and do the paperwork that was needed. We thought that, 'cause the idea was, we wanted the grants with it ready within the week of getting in, we are still waiting, we are still doing everything."

Fay. "They decided to go ahead but as you see we are still waiting. There is a tussle between the County Council and the Borough Council. The Council recommend what needs to be done and the Borough Council say 'yes' or 'no'. regarding the finance."

James. "And they are still waiting all the paperwork and then if it's not dealt with within so many months they have to re-assess. And we are now being re-assessed because they were too slow in dealing with it."

Fay. "We have been made very aware of the cost of the budget, mainly because our occupational therapist has made us aware of this and that there are so many slices of the cake to go round."

Debbie's contact with social services was also limited.

"I met the social worker at the CDU when I saw her perhaps on three occasions. I think it's a token on their part because I was a new name on the books, so they have to come and see him. She didn't do anything, she didn't help out, she didn't give me any advice and that was the end of her, just came along and went. Alec had no contact with social services in the last six years since seeing her.'

Janet and David had an equally negative experience to recount:

Janet. "Well, the only contact we had with Social Services. We had some respite care and they paid for that. But that's about it.

For some reason, I can't remember who it was now, but I was asked to find out who the social worker was and I rang, whoever the area superintendent is, and they said we didn't have a social worker, we only - when the case is closed the social workers go off and do something else. They don't have the manpower to keep the case open, so they close it if it's not much of a pressing problem. Really we've never seen a social worker."

David. "Well, the only reason we had to see a social worker was because when Simon got to thirteen, fourteen, he began to get big and heavy and difficult to lift and we've both got back problems as a result of all the lifting and also as his back problems were starting up it was very, very wearying. And for years we had people saying to us 'You should get respite care' and we were saying 'Well, no, we wouldn't send the other two kids out for respite, why should we send Simon out?' It's not a problem but it was getting to be a problem, we began to realise that we needed a break. So we applied for respite. The other two children needed time with us on their own because they do miss out an awful lot. So we applied for respite and, again, the other thing was, when we had got some respite places I thought 'I wouldn't let a dog in there, let alone my own child'. And a friend went to a coffee morning in Heathfield [a residential unit] We went along and we were just charmed by the place. You know, the minute you walk in to these places you've sort of developed sixth senses by then. It was full of human beings, it wasn't robot, it was human beings and I thought 'Yes, this is wonderful, David'. Well he was going to a house for respite not so he could sit in a corner and do nothing. He had a place to

stay and he had a home so we asked 'How do you get in here?' and they said 'You've got to have a social worker' and because we'd never had a social worker we phoned up and said 'Can we have a social worker please?' and this is what it's for, and we'd never asked them for anything before, and then they said 'No' we didn't qualify because we've got our own house, doing work, you know you're not the same as .... No, I mean, if I'd dumped him under the door, you wouldn't do that, I know that if I did something like that - all right, you know I've been in the post office and saw someone who said ;Oh, yes I've got him into that nursery'. 'How do you manage that?' 'Well, I just phoned my social worker and said I felt like hitting him, so she got me a place right away'. And I thought, I should do that you know. Yeah, well she'll have a lot of other things going for her and I've seen a lot of people who play the system and - so anyway, they turned us down and I was absolutely furious, anyway, we appealed and went to all sorts of meetings and I was quite political as far as disablement went, and eventually they said they would give us respite."

Angela. "To be honest ... the only time it's really bugged me was when we moved here. We moved in July and we had a stair lift in the previous house. So we thought, right, we will apply but we won't probably have much hope of getting any financial help. My husband actually works in the business of supplying disabled people with bars and aids like that, we'll try. If it doesn't work it doesn't work. So we tried and the attitude was, you know, look, we are not here to provide you with anything - if you can afford it, you buy it yourself, kind of thing. And then someone said 'Oh no, we can help, we can definitely help, we can give it on this budget or this budget'. And in the end we did get support but it was like weeks and weeks had gone by and they still hadn't ordered the stair lift. it was just driving me bananas. Why can't they just give

us a clear answer, you tend to think. I don't know if it has to do with these people, they just don't know what they are doing."

Sophie. "I've got a social worker now, apparently we had a social worker for a while but I never saw the first one. It was one of those things. If you had a review you've got a social worker and you feel like they haven't even met him. But the social worker I've got now, became involved last Christmas, is very good. She has helped me to get things, you know, this social worker that I actually see has done more in the couple of months that she's been involved rather than everybody else ever has. I know I could phone her and she would be here. I had to wash and dry his clothes every day and she came and she realised I can get your food delivered. Because he was wetting the bed every night she managed to get a mattress cover. I couldn't get a mattress cover anywhere, she sorted one of those for me and she managed to get me more care, she is very good."

Anne. "Once we put up this six foot fence that nobody would help us with the cost of, when we first moved round here. Council said no so that cost us £450 to put up, save up, that's it. And then last year, no the year before, well, they're sympathetic if you're a parent on your own, or you're a junkie, yes, you can go in and get it, because all the other girls sat there, well if I get such a money I can go and score. Which they obviously do, because I know, basically, you know.. Neighbours have new clothes all the time. I admit they've got six children but they get a lot of money and three of theirs are special needs, one of them doesn't go to school though. No, we don't have a social worker. It was actually the manager that spoke to us at the social services. But it seems that an uncaring parent who's not bothered about the school, well, they can use the money to get whatever they want."

The above views were representative of the experience of the majority of the Northern parents. However, three parents expressed very positive views about the support they had received.

Sylvia. "She's [daughter] got a social worker who is very good and really goes out and gets to know all that she thinks she needs to know and if Paula gets any problem she will ring her and she will liaise with the careers officer and college and anyone else. Paula will ring her and she will give her advice and support over the phone and she will write letters on her behalf if, say for housing or something like that, but she is there just for support really although Paula is very independent so if she wants support she will ask for it. She doesn't get it automatically, she asks for it and then gets it that way."

Janice. "They have been absolutely wonderful, the social worker that we were appointed, who is an older person, she is extremely experienced, extremely astute and she is also very gentle, very listening, and very kind, and therefore she has assessed Jane perfectly and her needs. But she also looked at the needs of the family and she has managed to draw me on things that probably have been left unsaid by somebody who wasn't so experienced. She has fought for Jane's right to have a comfortable life 'til she leaves us and she has fought hard for that and she has also got a lot of stick from the education department as well. So she has really fought on our behalf,"

Helen. "Yes, we have a resource worker who takes David out once a week. He's very nice, they go shopping and we have been involved with special services. Well, we haven't actually got a social worker now because she's gone somewhere else. So we now have a resource worker, the lady who will take David out. And she said if we had any problems she will be that sort of person who

will sort things out and we have spoken to the head of the team. I think it is the team leader really. She has been involved with the meeting."

By and large the support provided was in the form of respite care, adaptations to the home and aids in the home. Whatever the type of support provided, and the level of contact with a social worker, the accounts of the Northern parents clearly point to inconsistency in provision. Notwithstanding, parents welcomed that support. Parents were also asked to develop their ideas on what kind of services they would like to be provided, and whilst some parents were able to expand on what they would like to be provided, others found it difficult. This appeared to be a consequence of their having had little contact and, consequently, were unsure about what sort of support could be provided. The following will demonstrate this.

Denise had not been in contact with her social service department, so as a consequence her thoughts evidenced the view that without contact parents are unaware of what services are available.

"Never having had it I don't know. I don't think, right from day one, when you're told something's wrong with your child, there's no support whatsoever. You're not told what support you can have. You aren't told about financial aspects. You just find out about it by stumbling along. I don't think there is any support."

Mohammed. "Well, I don't know if they can do anymore, I was thinking of a ... well, you, I dunno, I have made a case with the house you know. I would like a bungalow type of adapted accommodation, an accessible house where we can live. This is all right for the time being but it is not ideal. The doors are cramped and ....."

Adele expressed the view that she preferred it if professionals did not 'interfere'.

"It's going quite well really. You don't want to interfere with 'people who know best' do you? This is the problem you see. Well, that was ideal, that children's service in London, and then it had to be run down and there's no such thing now."

For Sandra information was an issue.

"You don't always know what help's available, and I found personally that I found out about different groups, self-help groups and financial help and everything new from other parents. Not from social services."

Susan. "One thing that I have learned and what a lot of mothers do say when you do meet them at school, and you tend to find out more off other parents than from the social services or from your own doctor or whatever, you know what I mean? The contact with the social services is a bit sketchy. "

Ruth. "Last year Helen went to the Eric Jones Centre, [a Day Centre for Disabled People] there were kids with problems from younger children, normal children if you like, normal behaviour so that anybody would know that you were different. She had a few comas so at the time they actually supported me getting her to the day centre for the six weeks school holidays. Then I went in for three days a week or so. it was just to get her away from, to get her some sort of interest because here she hasn't got anything, nothing within this area that she could do. I mean the young one was seventeen coming up to eighteen. It's not very good but this year I don't think funds will allow it. I would have loved her to have the opportunity again just because she meets other people, because she wouldn't have met others. It was just that way, I think, but the way finances go ....."

Fay and James.

James. "I think the first thing would have been easier if there had been a central compiling of all the information. I think right in the beginning, when Louise entered our world, I think the hardest thing was the repetition, and all the different people, the professionals. We had to keep recounting the whole experience and I think as parents that was very dramatic, and we've got other younger children who were involved as well, and, as we've gone on, we've gone through the same thing again. You had the psychologist, we had people coming into the home and you find you are repeating all the same information, I think some way that could be lessened. .... one of the biggest problems that has bugged our system is the quick turnover of the people in the profession. A lot of people have stayed six months so they go somewhere else to do another sort of course, they've gone on retraining, they've moved to another department, and we found that a lot, particularly with the physiotherapist, the speech therapist, the OT's, people like that. I know that has to happen but there ought to be more continuity."

Sylvia. "What would have been of benefit to me would have been something to read, like a leaflet or a book, that could have sort of been given in the beginning when the child is first being diagnosed, or whatever, and like moving to the schools, like milestones, when they go on five, something then, like what might you have to expect, what's available in the area, you should be thinking about...but it should be available in an easy format. I always maintained that I have to always find out myself. I remember once finding something out and I phoned up the welfare rights people and they said that they heard of that. That's not the case, this is the new law that come out. I can't remember what it was about but no one came and told us about it. If I know about it

and the welfare people don't know about it, what's going on here. But we have 'Disability Now'. have you heard of that? That's a very good resource of information so you know I tend to get it from there but I found out over the years, I found out things by myself."

Although the Northern parents mentioned a range of support needs which they felt would be of benefit, two elements emerged above others, these were:

- a need for clear information to be provided and
- relief for parents providing care.

Evidently parents did not, generally, feel that they received much support. Consequently, it is reasonable to assume that parents themselves might feel that if support for them had been limited, then they might be cautious about the ability of, in particular, social services, to support their disabled daughter or son in the long term. So, following on from the discussions on support, parents, in particular mothers, were asked about any obligation they might feel towards their disabled child and whether they considered that there were expectations placed upon them in relation to the provision of future care for their disabled son or daughter.

EXPECTATIONS AND OBLIGATIONS

It was evident that the Northern parents generally felt that they had a greater obligation to provide care for their disabled child than for her or his non-disabled brothers and sisters. In addition they felt, albeit tacitly, that there was an expectation from the wider society that they would continue to provide care. This caused parents to be anxious and therefore they tended not to look into the future but to operate a philosophy of 'taking one day at a time'. The future was usually viewed with trepidation and uncertainty, as the following will show.

Denise saw Thomas as continuing to live at home with them.

. "Yeah, we're looking that Thomas will be with us all the time but William's nearly 14 now and we can leave him for certain times on his own whereas you wouldn't leave Thomas. Thomas can't be allowed to go out because, on his own, apart from in the garden, 'cause he could go off. If somebody spoke to him 'Come in my car' and - well, you've got to keep protecting him. I mean William will go off at some point and leave home but I don't think Thomas ever will. And the educational careers officer, she asked us in the other day and asked about putting Thomas in a residential at some point. We would if he was eighteen or nineteen, or whatever. It would be natural for a normal child to go to university so we would, because we want everything to be as normal as possible for him. We haven't up to now, we would never send him away but he needs looking after. We would do later because it's something like progression. But I'm sure he'll always come back. In fact he'll probably be living with us. Which could be a problem for the future because we're not always going to be here. I mean when William was six he once said to me 'I'm not going to get married', and I said 'what do you mean?' and he said 'I want to look after Thomas'. So even he feels some obligation."

Angela stressed her view on her different levels of responsibility between Alan and his sister.

"Elaine [sister] is getting older, she has always been independent, always sixteen you know. I think as I watch her growing and moving even further away it's like you realise how much they need you for the kind of things I do for Alan. She brings herself to school, you don't have to think for her, she knows what she wants and she sorts things out, she is organised, whatever she needs to

do. If Alan wants to go to watch football on Saturday afternoon it needs to be organised, it's got to be sorted. They have always been my kids, no matter how old they are, but what would be expected of me is different than the other two, at least that's how I envisage it. For the other two I'm going to have to be 'there', not interfering, not trying to tell them how to live their lives, but be 'there' if they need me. Whereas for Alan I think it's going to be, I feel I've got to watch over him all the time to make sure he's getting what he needs, he's not being abused by anybody and that he's happy. I feel a great responsibility towards him."

Debbie also identified differences.

"With Jo [daughter] you feel that there is a future, you know, which is progressing. While she is reading she will go through the system, bong, bong, bong, middle of the road all the way through. She will do whatever she wants to do at the end of it. She will go and live her own life and we just have to give her the support as other parents are doing with their child along the way. But with Alec it is not going to end. I don't feel that it will and try not to get upset. It's just his future, the obligation to Alec is long term, well with any child it's long term but it's tiring. So the commitment is just totally different and yet it's so frustrating to think that another disability and he could be looking at a future, he could have been looking for a job if he had the sort of disability that placed him in a wheelchair, that he could still function, his brain still worked like yours or mine, he would be more accepted by society. If you structure it that way, this is it. I'm not totally bleak in that I don't think that we will find something that would suit his needs. It's a totally different kettle of fish really between the two of them, it's quite frightening what the future holds."

Sophie conveyed a sense of desperation when talking about the future:

"I've been with a parent today and she has a son still at home at 21. He's like Joe Bugner, he's six foot odd, the house shakes when he moves about. She says people who put their kids in residentials are dumping their kids. I feel that if I get to a point when I can't carry on I worry that people will think I'm dumping him. It's awful when you hear other parents say that. I've got to keep him with me, it's what other people are expecting. I've got friends who come and see me and after an hour they say 'I've got to go, I can't take it'. If I was to turn around in a few years and say 'I can't cope, I'm cracking up' they'd probably call me rotten, well they wouldn't really if they were good friends. But you know you get that feeling.. I suppose I do feel a greater obligation."

Janet and David considered their obligation to be different, but not less than for Simon.

Janet. "I wouldn't say greater obligation but it's a different obligation. I mean, because the obligation will be more long term. The other two will, hopefully, get their exams, go to university, do what they want to do and then they'll go off to lead independent lives. I can't at this stage see Simon ever being able to lead an independent life. So the obligation is ongoing. Really, it's different, you're looking for the best for your kids whatever that may mean. And we will care for him, I suppose, I mean , I don't know, it's crossed my mind recently that I don't know how much longer I can go on doing it, physically, because he's getting heavier. I'm getting older and perhaps getting more and more knackered and, I mean, I suppose there will come a time when I can't do it."

Sandra felt the weight of others expectation of her

"Even the other children, as well, just assume that I can sort him out with everything. Obviously they're going to grow up and go out

and make their own life, but he isn't you know, he's always going to be our responsibility so you do feel different in that respect. You know, more time and I think it's more emotionally draining. We've discussed care in the community and where I think he probably would benefit from it. I don't feel ready to let him go yet so, you know, I don't think, it's difficult, it's difficult really because we still see him as being young where, I suppose, if it was somebody on the outside looking in they would probably think he would benefit."

Sylvia felt that she would continue to care but that the nature of her role would change:

. "It's hard really, I mean I still want a role for Paula because I don't stop to be a mother but my role will definitely change, like who she is now. She is so independent, I mean washing her clothes and someone irons them for her and I make her meal for her but I mean she is well able to phone a take-away and get a take-away but I think it would be nice to have someone to take away the worry, you do worry quite a bit about Paula well I do about health and stuff that worry me a bit. I suppose I still have that role but I think it will be a bit removed 'cause she won't be living here, she will be sort of married and have her little sort of thing. She's got that now anyway but there is time when we have to think, 'can we do this?'. "

It is evident from the above that mothers are keenly aware of the possible longer term obligations for their disabled child. Gender differences surfaced in earlier sections and they also featured in relation to the nature of roles performed by parents when caring for their disabled child. The next section will, therefore, explore parents' views on how they saw the roles and tasks each of them performed, as varying according to gender.

ROLES AND TASKS

Differences emerged between tasks and roles. These tended to be split between physical care, leisure activities, attending meetings, and being 'on call'. Mothers predominantly provided personal care, attended routine appointments, and were available if systems broke down. Fathers tended to be involved in significant meetings, important decisions, and leisure pursuits. Fathers also provided personal care but this tended to be constrained by the sex and age of the child, inasmuch as parents felt there was a sharing of care when children were young, but when they entered teenage years there was a separation based on norms surrounding what was seen as being acceptable for a man to do, in relation to a young woman. These points will be evident in the following accounts.

Janice commented on how she saw the separation of roles.

> "Decision making, yes. He tends to come to initial and important meetings. I tend to carry on with the parents' evenings and the general run of the mill because I'm at home and he's got quite a high powered job and a lot of responsibilities. He's in private practice and a lot of his time is taken up but he's a good father in the sense that he is there if I need him and, yes, we do make all the major decisions together. Obviously, no, he more or less doesn't attend to any of Jane's physical needs and only did when she was a baby. As it has gone on it has always been me. She is quite difficult to handle. Not difficult if you are a trained person but for anyone else .... She is now going on eleven, her joints are retracted, she is not easy to handle so he's not involved. He tended to be more physically involved with them when they were under two."

The significance of gender and personal care was also mentioned by Alice:

"Well he does, he does a lot of the running about with her. You know, if she's got to go anywhere if we're going... she goes to a youth club and so on in the evening on a Friday night. He takes her and brings her back and that sort of thing. But it's more difficult for him because now she's an adult girl. So he can't do the things that I can do for her. Because it's not right that he should do them. So that's the only reason. As far as support goes he's there for us all the time but it's just that if she wants... If she'd been a boy, well, he'd probably have had to take over a lot of the things that I do but because she's a girl he really can't do a lot of the things, the bathing and everything, you know..."

Sophie identified how attitudinal differences impacted on her role:

. "No, he's quite pessimist about, you know, he is never going to play football, he is never going to understand the game of football, so he has never taken him to a football match. My husband and I have quite different views on how we see Kevin's disability. My husband is more upset for his own feelings. I say, if you could just take him to a football match for ten minutes you will have done something with him, social. But it would upset him to have to come out of the match after ten minutes but I say 'your only upset for your own feelings'. If Kevin had ten minutes it was worth it. It's been hard for my husband because he has not got the son he thought he was going to have really."

Pat's situation was different and she commented on how having a new partner led to the need for some caution:

. "I think he is quite, he's come into Gail's life at a difficult time. She adores him and that really isn't a problem, but I think he is very aware of the fact that she is growing up, that she is adolescent. He's wonderful with her but I think at times he has to back off 'cause he doesn't want her to get too emotionally involved with

him, 'cause it can lead to all sorts of problems. She's a very affectionate girl and I think he's very aware of all the things that it entails, you know, what I am trying to say to you? So he's very good, and yes, very much so, really, to take them both on at his age."

Janet and David pointed to differences over time.

David. "It's varied. I mean when I was, when he was young, I was working in hospitals. I'd leave home Friday mornings and sometimes get home Monday night, too knackered to drive sometimes, and he'd look at me and say 'Who're you?' So during that time certainly it was mostly Janet. I suppose recently, physically, it's me because of the sheer, his weight basically. Lifting and carrying."

Janet. "And also, he's eighteen and he has to be shaved in the morning and all the other things that go along with being an adult. Much better to let you deal with it. But he ah, when he was younger, physically, it was mostly me but now, it's, for a long time. It's mostly you. David bears the brunt of it physically."

Debbie pointed to a connection between gender and physical activity:

"The older Alec gets the more obvious the physical side of things is. Alec loves tumbles, which I've been able to manage with him, but he is getting big now, it's only dad who can cope with that side. I must admit I tend to move the duty to Jim, my husband, in the weekends. I don't ignore Alec but I practically move Alec to Jim and I know that he's managing him, shadowing him, but they do things together which, I mean I don't like heights so I don't go into the loft or anything. Alec loves sitting on top of the roof, him and his dad go up to the roof and him and his dad go into the garage

and do weights, all that sort of thing. Typically boy and dad relationship. But likewise with Emma [daughter] she feels it and every so often if we had a really bad time with Alec, every so often if things have been really bad she has a day off school and we do the town, we go to a film, we have a girls day out because she needs that time. She needs that input back into her life really, because, oh she has heard ever since she was a baby, Alec this, Alec that, we are taking him here, there, everywhere and she has been brought up with this and it's a stress for her. He falls into the thing of again being out at work so it's usually me who does all the, if there is any visits to be done it's usually me and I sometime think 'what about dad' because it took him a long time to accept, longer than me really, to accept about Alec. He is not an easy person to, he won't open up, even to me, he only opens up from time-to-time and I just wonder because it's obviously a very stressful job and I wonder how much his stress level can actually take and I feel that he should be given the opportunity. This is something that perhaps again should come from social services. Whether he would do it through them, but through some sort of organisation. I mean he gets the opportunity to get stress counselling at work but who is giving parents stress counselling?"

Along with obligations, expectations and gender differences in roles, two other elements caused the Northern parents to reflect. They were intertwined, and were concerned with the long term potential of their disabled child, and how the role of parent and advocate were taken as being both a responsibility and a duty. Consequently, how parents saw their role in relation to representing their disabled child, or advocating on their behalf, was seen as an important issue and will, therefore, be explored in the next section.

LONG TERM POTENTIAL

Parents views of their disabled child's long term potential were frequently fraught with anxiety borne of uncertainty but, as demonstrated in earlier accounts, parents largely saw the future in terms of their own responsibility to provide care.

Denise saw 'staying at home' as being the least undesirable of the options she considered to be available to Thomas:

> "I think he's going to be capable of doing some bits of work, I don't, I wouldn't like him to go to one of these centres and not do much. We discussed it and we'd rather he stayed at home and we support him rather than him going and just doing nothing. But I think he's capable of doing work, like stacking shelves at Tesco's, or push trolleys, or clearing tables in McDonalds. He's capable of something, it's just getting him into something, that's the trouble."

Pat saw the difference between Gail's physical development and her intellectual ability as being a major factor in any thinking about what Gail might go on to do:

> "The headteacher did say that I had to accept the fact that she may never improve. I think she has been on this plateau now for quite a long time and, I think I know it's hard for us to see it because we see it every day, but I don't really see her making much more progress. To be honest with you she may have a spurt, she has had the odd spurt in the past but she hasn't really had one for quite a while. Physically, yes; growth wise, yes; she's extremely mature but mentally I think we're operating at about a

four year old level. She talks, I mean socially she's quite a lot older than that but her skills are really quite weak. I have given it some thought but I tend to not try and push it. It's very, very, hard in some ways because of the way she is. She's still very much a little girl and yet she's growing up very fast physically. I think that worries me more than anything, you know, am I always going to be around to protect her because I feel she's at a very vulnerable stage."

Alice conveyed a pessimistic view of the future:

"To be sat here doing nothing. I don't think anything else will happen. I don't think, I mean this is why I'm pushing now because of the rest, because once she goes into adult services, a couple of days, a month, or whatever it is, they'll say 'Well, that's what you got before, You managed then, well, that's all we're going to give you'. I'd have to be here every day of the year. I want her to be able to go to respite one week a month.....not only for her but for me as well. I would like her to go into some sort of sheltered accommodation but they're few and far between because that's what everybody wants for their child. But it doesn't work like that. As I say you've got to push and push, all the time."

Susan saw the need for continued support:

"I think she is going to be reliant on us for a long time, she is OK as long as she is not stressed. Stress just sends her haywire completely. She is going to need us for a long time now and we are worried what she is going to do. You see, is her lessons going to improve work prospects because we are worried about her work prospects being a bit grim anyway if she picked up in all her lessons anyway. It's not three years yet and I think anybody with a disabled child has a lot of stress."

Debbie was beginning to consider the future with trepidation:

"To me that is a frightening aspect and something we only just started to even allow ourselves to think about. I wasn't ready to face it. I don't, I don't know if I'm ready to face that one but it is quite daunting because at the moment it is sixteen and that's it."

Sylvia felt that practical difficulties would create barriers:

. "Well, she is leaving very soon. She is desperate to find something to do. She wants to go on to voluntary work but she is not, sort of getting anywhere with her career plans at all. People have got negative attitudes and not only are they sort of discriminating against her but she can't physically get into most places. So even if she gets a job somewhere there is big problems with the toilet and getting in and out of the building. Transport is the main thing, specialist transport is so expensive. I mean at the moment it is fifty pounds a day to travel to college."

A clear exposition of the 'day-to-day' approach was articulated by Ruth .

"Well, in fact I used to worry. I used to think long term and now I can't. I have to think day-to-day. I don't want her to be in a day centre full-time, she has got potential but not enough. I don't think there are other young people that have left college and, actually, it's quite brave to get to here. I do know one young man. He has not been employed. Very hard. I don't want to think. I want to deal with it when it comes."

Adele. "This is the big one, isn't it, and I don't know. Apparently at school they do wonderful work experience programmes there. But it's thinking about what he would be, you know what I mean? Very difficult 'cause of the short term memory, which is a nightmare. I just don't know."

Janet and David were postponing thoughts on the future and illustrate how consistency and stability enable them to cope:.

David. "The $64,000 question, that is. Well, I mean they were saying at his last review that we need to start thinking of post college placements and things and whether it should be something residential, or whatever. Or whether he can stay on at college a little longer. To be honest we haven't really, I suppose, in the denial phase, you know something's going to happen again but it's frightening. It's frightening to go round and look, you know, our life's sort of sorted and comfortable at the moment. We've got a routine and everything but, I mean, what If I'm frightened to go and move on somewhere, look for something else? I mean I dearly hope that my kid stays on at college for sometime longer, for as long as he continues to show signs of progress and college are happy to have him. I mean, I know some people have been there until they're twenty-five. Now a lot of people would say 'You can't do that' but I would like that because I am terrified of moving on to something else and it breaking down and I can see him being at home with nothing. I really don't know. I should go and find out more about the future but I'm frightened to look at it because everytime I've been to look for something life's changed or he's sort of moved on somewhere. We always end up, certainly me, very depressed. You end up in tears and recounting every bad phase you've had in your life before and going through the whole thing and imagining what he would be like now if what happened to him hadn't happened. You know, and not being able to visit friends who've got children who were born at the same time because they've got independent lives and that brings it back to you. That whole thing 'Why did it happen?' and everything."

Angela's ideas of a form of supported living was a recurring theme:

"I'd like him to have his own place with his own care. I don't know if he will ever reach that point to want to do that. I think he probably will. He is going to need the hospital, I think, for the rest of his life. But I want the support to be what he needs but, being in the profession myself, I'm very aware of how bad it can be, how badly people can care for other people, how many can be abused and used, and there is no way I'm going to let that happen to my own son. I'm just going to keep him with me forever, because I couldn't live with it if something did happen to him. But part of me realises that he is an individual and that he's got a life too and be that person and do his own thing if he wants to. But at the moment I can't see him wanting to leave home, he loves spending time at home and he is normal, isn't he? You grow up and you eventually go out and do your own thing. For me that will do it, you know, thinking of him with youngsters of his own age and being cared for, hopefully. That will do it for me."

Clearly many parents felt that their daughter or son would remain at home to be cared for by themselves. However, a number expressed the desire that some form of supported living offering care and companionship would be desirable. Whichever position parents adopted the general view was that their daughter or son needed an advocate. The key issue being, who best could perform that task? The issue of who was best will be seen to be something of a theoretical question as parents often appeared to be the sole person in any position to act in that role, as will be seen when parents' perceptions of advocacy are probed in the following section.

PARENTS AS ADVOCATES

It was evident that parents were concerned that there was a risk that their daughter or son would suffer abuse, neglect, or that their son or daughter's

wishes would be ignored. With the exception of a few instances where parents felt their daughter or son were assertive in their own right, the clear message was that parents had to act as an advocate because there was no one else. Advocacy was also seen as being part of their parental duty.

Advocacy as part of the parental role is clear in Helen's response:

> "Well, I feel it is my job really, because I think I can understand more than everybody else and the kind of things he likes and I feel that he would enjoy. He is not capable to make decisions for himself. I mean he will tell me when he goes to respite and he really enjoys it and I said to him if he likes to spend some more time there and he said 'Oh yes, I loved that'. So I haven't done it without consulting him, then he wouldn't turn round and say when he was nineteen you know. I mean we went to college but we didn't take him with us. I don't know really, I think I probably would visit first and then take him. I think he would say if he didn't like it. I think I just sort of know really."

The necessity for advocacy was confirmed by Alice but in the absence of anyone to take on the task she was clear that she and her husband had to take on the role:

> "If we don't do it nobody else would do it. Having a disabled child makes you. I was always very quiet. I wouldn't say no to anybody but because over the years every step of the way you have to fight for what you get, everything you want. You don't really care what you say to anybody because at the end of the day you've got to get the best you can for your child. Everybody is the same. All the parents are the same because you don't get anywhere if you go in and you say 'No, there isn't any money available'. We've always done it. There are things to do for her, washing and bathing her and so on, that I've always done since she was a baby; so to other

people it would be a big job. Because I've done it all her life it's no different now than it's ever been. When she came to be sixteen - we get the allowances for her - when she came to be sixteen he had to come and interview me to see if she was good enough to look after her money. As far as I'm concerned it's a joke because 'what do you think I've been doing all these years?' It's still a joke. I mean Linda doesn't go short of anything. She gets everything that any other child gets. She's got a television, a video, a cassette, she's got everything that the other kids have got. She is treated no differently than a normal child but as far as decisions go, we always have to do it. So it makes no difference, it's just part of your life."

Janice was unusual inasmuch as she had the co-operation and support of a social worker. However, she did make the point that the way in which they made those decisions did not differ from the way in which they had made decisions for their other children. Janice's view, therefore, was further evidence that parents saw advocacy and decision making as an almost routine aspect of parenthood:

"Yes, absolutely. Although I have the backup of my social worker now and that is absolutely wonderful because she is who she is. Had she been not a very good social worker I think that would have made the situation much worse. We are her parents and in the other sense that we take decisions for our other children as regards their education. I mean they didn't decide, our children didn't decide where they were going to be educated from day one, or even at eleven. You know, we'll turn around and say 'well, sorry you've got to leave your friends because we think it's better that you are educated at such and such' and, in fact, they didn't have any say, I mean, yes, you are making decisions for them and then with them, but we won't be able to make decisions with Jane, therefore it is an ongoing thing. So in a sense while our children

are being, say pre A level because I think in A level, then they are coming up to make decisions, saying 'well, we want to stay at school' and, in fact, one decided to stay at school for A level and one decided no, she was going to skip school and college. We all sat down and we talked it over and I think at that stage they are making decisions about their future as regards to education, obviously not other things. But that would never come for Jane so, yes, I think we have to say while we are in sound mind."

Margaret saw Hazel as always needing someone to ensure she was all right:

"Well, yeah, I hope so because I always speak for Hazel. If there was something she really didn't like, she'd tell you if she didn't want it. We still do, well, we try now 'cause she's an adult to get her to make her own decisions. We won't be here all the time, you know, time you learned how to decide things for yourself. Still, we're always doing it. I should be there, making them for her. Hazel's told me that's what they work at in college. To try and get them as independent as possible but I can't really see her handling her own affairs and financially, I think she's going to need somebody there to check that she's all right."

Sandra's response was further evidence of parents acting as advocates out of duty and necessity:

. "I do listen to what he wants as well and I think I know what his capabilities are, to a certain extent, and I do listen to other people so, you know, I suppose if there was something he wanted, he really wanted to do, then I would help him, you know, I'd fight for him to get it. It's just part of being a parent, you know. I don't feel as though, you know, I feel it's just the same as for any other children really. You know, sort of picking their schools for them. I mean, it's not as though he can go out. He does, I try and enable

him to have a social life but he doesn't have the same social life as the others. You know, obviously he can't just go out when he wants to, you know, and I have to arrange so he can see his friends or go to a youth club. Something like that, just got to arrange for myself or my husband to be here, you know, or enable us to take him or somebody to pick him up and, you know. Whereas the others just go themselves."

Gender differences featured in Angela's response:

. "I feel that the men in Alan's life are a bit backward at coming forward when it comes to making decisions. I don't know if this is a trait of the gender but there's so much value in what a man thinks. I try and pin my husband down 'what do you feel, what do you think about this?' His way of looking at Alan is completely different to mine and that's healthy. I think you need the difference. With Alan being a boy, well a young man, much as I know him I don't know what it's like to be a boy. Whereas Brian does, Alan's father, because he's not really involved, I show him all the reviews and reports but he's not really that concerned to really get involved, so he says 'it's up to you, you know him best'. I trust myself to make the right decision for Alan but at the same time there's this kind of, it's going to be a big mistake, things like having operations as well. He's had loads of operations and every time one comes up the surgeon will say 'what do you think, do you think we ought to do this?' and it's a decision I know I've got to make and really only I can do it; but it's for someone else, Alan, is it really fair that I should be doing this? He has had operations that have done him no good at all and I think 'well, that was a waste of time', or he has ended up worse than he was in the first place. I think in some cases Alan's been a bit of an experiment because his condition is fairly rare and they've not done it before on a kid with his condition

so there is a certain amount of experimentation even though there's plenty of research into the condition. If you read it, it is quite plain what's the best way to go, they still have to try. You get very battle hardened and very wise to the various egos that are around. I knew about them already because I was a nurse. They know what they are talking about and they do genuinely have Alan's interests at heart but there have been times when I have just thought 'well do we need to do this again?' There are operations he's had time and time again and they have not helped and it seems 'is this man never going to learn, it's not going to work.' Every time he goes into hospital I'm waiting for the next mistake 'what's going to happen this time?"

Several parents considered their disabled child to be assertive and well able to make their own decisions and act upon them.

Helen. "She knows her own mind. I can't make decisions for her. She's sort of strongly motivated sort of person. She just gets on with things."

Ruth. "She doesn't need one she's self advocating. In the past I've stuck my neck out for her but now she's got to that age when they've got to take her seriously."

Sylvia. "She's very determined and strong willed so I don't tend to make decisions on her behalf. She makes them and I just put them over. I remember one time we wanted to go somewhere and she said to me 'I don't want to go' and I said to her 'Well I think you should go' and she said 'I don't want to go, I don't need to be assessed because I know who I am, I know what I am, I know what I can do, what I can't do and I don't want someone who tries to tell me, you know, and assess me and say what I can do, what I can't do'. And then when they sort of persuaded her I had to say then 'well she

made her mind up, she doesn't want to go and she is not going and that's it' sort of thing. But it had been a joint decision on which school she's gone to."

The chapter has, thus far, been concerned with the experience of the Northern parents of having and caring for a disabled child or young person. Their views can be briefly summarised as:

- Parents being sceptical towards health and social service professionals.
- Having a disabled child has complex ramifications for family life and siblings.
- Mothers are primarily responsible for the day-to-day care of disabled children.
- Parent's felt that they would, and should, continue to provide care and be responsible beyond the age they would expect to be responsible for a non disabled child.
- Taking primary responsibility for the care of a disabled child places constraints on the capacity for mothers to pursue personal goals.
- Having a disabled child creates stress within families and relationships.
- Parents feel anxiety about their child's future,
- Parents receive little support from social service departments although they identify areas in which support would be valued.
- Parents, and mothers in particular, consider themselves to be their disabled child's advocate and have had to battle with statutory bodies and professionals at crucial stages throughout their child's life.

The object of this brief summary is to highlight the main issues identified by parents, and to summarise the implications for parents, of caring for a disabled child. The aim being to provide a backdrop against which the choice to send a child to a special school can be placed. For it is the latter issue which will form the focus of the remainder of this chapter.

SPECIAL EDUCATION

It was stated above that the Northern parents did not recount their experiences in ordered, organised packages. Although responding to a semi-structured interview schedule, designed with the aim of containing responses within pre-defined parameters, and limiting drift in interviews so that comparisons could be made with the resultant data. However, it was evident that the Northern parents did not see their lives in the schedule's pre-defined categories. It was, therefore, decided that the best way to present the data in a way that would make sense, would be to organise it under a series of sub-headings. It should also be recalled that it was decided to present the material chronologically so that it followed the 'pre-adult' life pattern of disabled children. This could have included the Northern parents' views of special education at, probably, most of the key stages in their child's life. However, it was felt that this would have dissipated the information on special education which would have made it difficult to sustain a coherent discussion on the role played by special education. Consequently, the chosen approach has permitted the accounts of the Northern parents to illustrate the impact caring for a disabled child has on a family. This has allowed the significance occupied by special schools in the lives of the Northern parents to be exhibited.

Responses contained in the following sections will begin to provide an answer to the central research focus, that is, an explanation for why parents choose special education. Responses will show that most of the Northern parents took an active role in the choice of school for their disabled child but that there were also differences which appeared to be dependent on the nature of the child or young person's impairment. It is also evident that schooling cannot be separated from other aspects of a disabled child's life, because where a child spent their day, and the way in which professionals at the school responded to the Northern parents, impacted, on mothers in particular, in ways which indicated that special schools perform a function which goes

beyond the mere provision of education. These responses are recounted below.

SUPPORT FOR PARENTS FROM SPECIAL SCHOOLS

One of the issues identified by the Northern parents earlier in the chapter was the lack of support they had received, and the paucity of information made available to them. Consequently, to form a bridge between the two areas, namely, the experience of caring for a disabled child at home and the choice of, and experience of, special schooling, the next passage will comprise parents' accounts of the support they receive from special schools.

The kind of support received from special schools by the Northern parents fell into three broad categories. Firstly there were para-medical services provided on the school premises, such as physiotherapy and speech therapy. Secondly there was what might be termed as 'emotional support' , inasmuch as parents felt a sense of security in the knowledge that their child was in a safe environment, and that staff understood the difficulties associated with caring for a disabled child. Thirdly parents gained most of their information from either the staff at the school or from other parents during the course of school activities. How parents felt about these will be evident in the following accounts.

Janice. "As a responsible parent you aren't rushing down to the school every five minutes mithering the teacher and obviously your children have to grow and stand on their own feet and sort their own problems out. The fact is Jane can't tell anybody anything. She is very vulnerable. She can't say I don't like. I am tired, I am hungry or she couldn't say if somebody was touching her inappropriately, as you would expect all your other children to be able to come home and say. That will never happen with Jane so

we have got to have somewhere where she can be watched. The problem was she couldn't be watched adequately at Pewter Hall [a previous school] things went on through no fault of their own. Here, because it's very much a small set up they are on the ball for every single little thing. I don't think I could have coped a lot longer. I mean I did because you just keep going on and I suppose on the one hand I just would have gone on, you do, don't you? There isn't an alternative. But things were very strained and that wasn't good for Jane. The other children I felt were beginning to resent her. That was very bad and also very worrying. There were a lot of issues going round in my head and for me it was a very, very, difficult time but now it's not because I know Jane is absolutely fine. In my opinion she is getting the best possible care that she could possibly have."

Andrew pointed to how teachers at the special school provided support over and above the routine expectation.

"The thing is you really feel, the thing is Sara's teacher has given us her own phone number if we had to contact her or anything. Well, I won't say that we expected that but you just don't get that in a mainstream you know. I can tell by the statement as well and the latest statement we've got now from here is more realistic than Gregory Lodge [previous school], the mainstream. The comments in the statement really sound as if they are talking about our daughter. The annual reviews at GL, they really went well adrift."

Helen highlighted how she saw a difference between mainstream and special school staff:

"At the school my other son is at, parents are the lowest form of life. The support and warmth and friendship that comes from special school, I think, is beyond compare. In comparison to special school, well there is no comparison really. We, I have a

friend with a child at special school and she was saying that we probably feel it more because we have the experience of special school. Other parents just accept it as being the way it is. We really notice the difference. Yes, they are great if you have any problems, they are very supportive."

Sylvia considered the main difference to be levels of communication between the different schools and themselves:

'I can't base it from other experience but I've got nephews. They were in ordinary schools and the support is really good from the special schools. It's more communication I think. You find out all sorts of things that you maybe wouldn't find out otherwise.'

Sophie. "If there's ever a problem you can ring up. You can walk in there any time. I have been there many times this year saying things that have been bad at home. We write in the diary more than they write back to us. I can write in it that everything seems to be falling apart over the weekend, you know. It seems that we had a bad weekend. On a Monday, like that happened on this weekend and the teacher had phoned me by half ten on a Monday and said 'right, we do this and this, have you done this? and I think we should try this'. The school always come up with an idea that we had not even thought of and when you feel it is the end of the world, it's just that fresh point of view. That's the biggest thing really. I know they are teachers but they are like social workers as well."

Nicola identified a readiness on the part of staff to discuss John's needs as being important to her:

"Well, you feel as if you can just talk to them and they're more friendly, I think, than ordinary teachers, if you could say that. But teachers I've met through my eldest son, well, it's a bit, you know,

it's 'they know better than you'. I go to parents meetings. It would have been nicer to get to a few more different things, but ..... I can just phone her up and talk to her about it. If she can't help she can get someone to ring me who can."

Involvement and collaboration were important to Fiona:

"You are more involved, I am more involved with the school. I am there twice a week for a start, helping out. But also you know what's going on all the time through the diary. It's communication all the time. They understand exactly, were other people don't."

The main advantage for John was the low student to staff ratio leading, to small class sizes:

"I think the main thing is size, there's only four in Edward's class, four children. All Edward's age, There are two teachers who're specially trained to teach autistic children. There's also two speech therapists who take Edward every day and there's also the psychiatrist who has him once a week. So he's really, this is in each class, so he's getting like a one-to-one really. Well four to one. We have a diary that we have to write in every day. They write to us saying how Edward's doing and little bits and bobs of information. We get mail every day off them about different agendas for parents' evenings. There's a new one where they're doing a workshop in the morning on bringing up autistic children. Unfortunately I haven't been able to get to many because I work shifts but the ones that I've gone to have been brilliant. They have different speakers that come every week to the school talking about autism. They're always, obviously, trying to raise money."

Sandra also identified communication as being an important feature:

"I'd say you probably have more contact because I have other children, you know, and there's no contact whatsoever, unless you

go to parents' evenings. So I'd say there's more contact. It's different at the college. More than the school because there was a constant, they had a diary so you knew every day different things that were going on. I sometimes don't get to find out things from the college because messages don't come home or my son forgets to tell me, you know. But because it's run as a college ant they're trying to make them more aware and responsible for their own actions and things, so we've had a compromise now. If I want to know something then I'll put a note in his bag and they will, you know, reply to that. It's very different actually having him 24 hours a day than going to school. Sometimes I think some teachers in their enthusiasm expected you to do an awful lot at home, but when you've got other children as well, or you work, then it's an impossibility."

Debbie recollected how she had felt herself to be an outsider when Alec had attended a mainstream school:

"I've got no support when Alec was in a mainstream school. I mean, I actively tried to get involved, you know, mum's help, but you were an outsider, your child's in the unit, you either got the 'Oh isn't it a shame' syndrome. Or you got 'she don't live round here'. You were an outsider. You would pull up in a car and they would look and say 'lazy article' she should be walking, because everybody else walks. At the school I accept that people are coming from a massive area but time is taken to arrange coffee mornings, talks in the evening to educate parents in the needs of their children, and to meet. It's nice to know that if I've got a problem there's always somebody there I can talk to, they will take time out for me. Today is an example. I had an awful time getting Alec ready but I know that there won't be somebody there waiting to give him an unauthorised absence. At the school the problems

aren't a problem because that's the nature of the children. The stress factors gone off me and it makes a difference."

Pat, a teacher herself, felt that comparisons were unrealistic:

"I'm not sure they're comparable, are they? I don't know really. We have a very, very well developed pastoral system at our school. I think the communication between the parents and the school itself is similar in that we have the same school notebook and if anything bothers me or if anything Gail's done, I can write in and I can comment on it and everything that's happened at school they can. So it's a different sort of care because half the children at the school can't express themselves, they can't explain what's troubling them. Whereas obviously a child in our school can. I think in both cases the parents are free to go in and say they want to talk to a teacher. I mean, we have the same channels, we have the parents' evening, at the school as well, with the individual class teacher where we can go in to talk about Gail's progress and so on, and I do feel that the doors are open, I can go in and speak to the Head whenever I want, or I can go in and speak to the family liaison officer. We have a specific lady who is a family support worker at the special school that we can contact if we want to. Same goes for, well, secondary schools vary, it's actually awkward for me because I actually teach in the school where my son is, if he's involved in something I can just talk to the person involved and, I think, that as a form tutor myself I do get parents coming in to see me. So I think that from that point of view, it's very similar. If I needed the emotional support and I needed to contact the special school then it would be different."

Fay and James added further evidence on differences between mainstream and special schools:

James. "It's of a different order, isn't it? bound to be but...."

Fay. "Yes, I think the mainstream approach to your other children is academic, academic attainment and more ability. Whereas the special school is more concerned, acquiring equipment to enable them to be educated. I mean in the review we spent a lot of time just talking about a machine and who is going to pay for it and who is going to get it when the fact is that this is a vital thing which should be here. Whereas with our other children the equipment they will need is there. In some ways, I mean, I think the most daunting is all the paper work 'cause every time you get this fat letter and you think 'no, it's going to take ages' and you try so hard to write the right thing and if you had a child like ours it's so complicated medically. It's absolutely exhausting. It keeps repeating the same information."

James. "I think I would be in favour of saying 'yes' because I think the school is there as a sounding board, as a backstop. If we do feel that there are difficulties that we have to address medically, or in some other way through social services or from other agencies or, particularly thinking about aspects of our lives that we have gone into today, the support is there."

Angela pointed to the compassion of staff at the special school and how this contrasted with how she felt she would be treated by mainstream school staff if she had a problem:

. "I think the nicest thing is just knowing these people are committed to what they do. These people actually care about how these kids end up and they put everything into it. Just knowing that somebody is doing that, to me, it means an awful lot. I can go into that school any time and talk about any problems that may have arisen and know that I shall be listened to and they will be concerned. They are not just going to dismiss it as a hysterical

mother, like a lot of people do with a disabled kid. 'Oh, she's just flipped' or whatever."

This section has highlighted how the Northern parents felt about the type of support they received from special schools and how they, generally, felt reassured that their child is cared for, safe, and that they themselves will be listened to and supported.

However, these were not necessarily the reasons behind the choice of special provision but rather the experience once their child was in attendance. The following sections will, therefore, consider the events behind the decision and the process leading up to attendance.

CHOOSING SPECIAL PROVISION

One of the main elements of the Education Reform Act 1988 was to extend the capacity for all parents to exercise choice in the schools their children attend. This attempt on the part of the Conservative government of the day to introduce consumerism and customer sovereignty into education, has placed a requirement on schools to produce information on academic performance. A consequence of this has been the growth of a culture of 'parental choice' whereby parents consider which school will best enable their children to achieve their full potential. Whilst the success of this strategy is a matter for debate, it does imply that parents of children with an impairment can also make similar choices to those available to their peers who have a child without an impairment. However, responses from the Northern parents did not suggest that they had been able to exercise choice to any great extent. Indeed, the choice of special provision varied according to the nature of a child's impairment, with responses suggesting that there were two broad categories into which the reason behind attendance at a special school could be placed. Firstly there were those where it has been assumed that a child

would need special provision. This either being implicit in parents' dealings with professionals or on the basis of their own understanding of how their child's needs would be met, or explicitly stated by professionals as being the only way in which their child's needs could be met. Secondly there were those parents who, for a number of reasons, had had to argue the case that their child would only have her or his needs met by attending a special school. The accounts will illustrate these differences.

Fay and James felt that because of the degree of her impairments Louise would need to attend a special school.

James. "Well, almost from the moment of birth because of what happened at Louise's birth. We were left in no doubt as to what Louise's future would be."

Fay. "When we first started, when she was much younger, we actually made the decision to keep her at home for two years. We made the decision not to send her to school because the school they offered us we felt was what we call 'bean bag bound' and they would not let her go with her own age range, they would not let her go into the main school because they felt that she was too weak and they only looked at her medical records. We saw a programme on TV about the 'multi-handicapped child' which mentioned a school in Southtown and we realised that we had only been looking inside our own authority and we made a point to journey up the motorway and once we got to the school I immediately knew that it was the right place for our daughter. We were inspired by the team approach there."

Professionals had provided information for Sheila because they considered that James had an impairment. Consequently, his needs would be met by a special school.

"When James was born we was told that, you know, he was brain damaged, so I didn't really know anything about special schools, Other than that they existed. I didn't know anything about. The Child Development Unit was one of the best sources of information in the beginning."

Sophie had decided that Kevin would benefit from attending a special school.

"I think what happened was that I rang the Autistic Society and got put through to a parent whose child was going to a special school at that time, I thought that that school would be the best for him. What she was telling me about what her son was doing made me think 'wouldn't it be great if they could do that with my one?'. I sort of heard about special that way. I thought the special school would be fantastic. I thought it would be good for my son. In my imagination I thought special school would be best."

Janet and David, both of whom were medical professionals, were clear about where Simon's needs would be met.

David. "We knew from very early on."

Janet. "Yeah. Very early on. I suppose really from the time that he started school it was obvious that it was not good for him to go to a mainstream school. There was an attempt made at integration at East Town College."

David. "And previously a unit integrated into a primary school which my two sons went to."

Janet. "But it was not err...."

David. "Miserable failure. Catastrophic."

Alice had concluded at an early age that Linda's needs could only be met within a special school.

> "I was sticking my heels in but I wasn't getting anywhere and they said she needed this, that and the other, but they weren't giving me any answers. So she went to Avalon, which is a nursery. She went there for twelve months, by the time the twelve months were up she'd been diagnosed as having cerebral palsy so the only option was Cliff [an integrated primary school] there wasn't anywhere else."

Helen felt that she had no choice.

> "Well, he had such great difficulties. Basically he could only just walk, just standing and taking a few steps at six. It was just pretty obvious really. In the early days I thought integration would be nice. I realised he wouldn't be able to get physio and speech therapy and those kind of things."

Janice highlighted Jane's medical condition as the major feature.

> "Well, if I can tell you about Jane's condition. We now know that she was sensorialy damaged, she is also blind, she is severely epileptic, she is non-ambulant, doubly incontinent, and she has malabsorbtion problems, and, given all those things put together it was evident at that time, although we didn't have the actual diagnosis. I mean it was quite obvious that she needed high professional care on a one-to-one basis virtually. So it wasn't hard for us to decide."

Sylvia made her choice because she saw that the local school would be inaccessible to Paula.

> "I sort of knew that all along because I knew the local school. I knew they weren't accessible and I knew there was no chance in

> the near future of them making it accessible. So I just sort of thought what would be next, where does it go from here and there wasn't much information at all."

Denise spoke of lacking knowledge and information about how Thomas could be educated.

> "I hadn't even looked into any sort of education at all. I didn't know it was possible for him to be educated normally but the physio who came, she said she thought he'd benefit from going to school as soon as possible and the only way he could do that, at the time, was through special education and if it ever became possible to put him into mainstream. But as it happens, it hasn't."

In Debbie's view she had been left with no choice other than to select a special school for Alec.

> "He was still an infant. He went from that language unit, we thought, to the second language unit which would have taken him to age eleven. He went there at five and a half and while he was there the first twelve months were lovely. Everything seemed to be put into place. He was a happy child. We were happy parents. Then things started to go stale and also his autism became more pronounced. It was then obvious that it had gone beyond language communication disorder and as non-experts even we could see that he was doing things that we were reading were classically autistic and he was becoming so miserable, so sad, so withdrawn, not eating his food all day long at school. Not actually fighting against going, he was happy enough to go but in the words of the teacher 'he wouldn't pick a pen up, he just played in the sandpit all day long'."

Adele had been guided by professionals.

> "'We just took advice. When you get involved you listen to the so-called experts and you're thinking 'Oh God, if he does need that then we'd better get it', you know. You're not an expert, as you think, at that point in time."

These comments imply that parents felt they had little option but to opt for special provision. Some had experience of mainstream but that experience had been negative, others were guided into choosing special provision by medical and para-medical professionals, others had considered that a special school was the only place their child's needs could be met. If this was the case then it is reasonable to consider how much choice parents had in the school their daughter or son subsequently attended. Intrinsic to that choice was the statementing process. The Education Act 1981 and, subsequently, the Education Act 1993 (consolidated into the Education Act 1996), contains the requirement that a statement of a child's 'special educational needs' be written down along with recommendations as to how those needs will be met. This process has become a key issue for parents whose children have particular educational needs, which it is considered cannot be met within the usual mainstream education system. The following will demonstrate how the statementing process and the choice of school are intertwined, and was the cause of high levels of anxiety for the Northern parents.

Delay in the statementing process was a recurring feature. Sophie spoke of this.

> "We were one of the families that had to wait years. He was actually the first sent to an assessment centre when he was twenty months old and he was past five before his statement was done. It was a very, very slow process. But when he was twenty months I was saying 'I think he's autistic' and, really, I knew he was, but it just took an awful long time to get that done. It was actually at Strathmore when the statement was started but he moved to another school and there was just, he'd moved to a third school

before the statement was finished. It was a long time. But he'd been there quite a while, he'd been there quite a few months when the teachers called me in one day, sat me down and said 'Have you ever heard of a statement?' I said 'No', you know, I just thought it was a bank statement or something, and she said 'there is a procedure'. I remember her trying to explain to me what it was and I remember just being baffled, thinking 'I don't know what you're going on about', you know, and it was all completely new to me. But I do remember her explaining how serious it was, a very important document. She was trying her best to explain it to me.' "

Sophie also commented on her feelings about the process

"I remember feeling 'what does this mean?' She was saying this was a legal document and stuff and I was thinking 'My God, what if they say 'we should take this child off her parents'. I remember feeling a bit panicky. I remember her saying that 'as parents you can put your own report in and that that would be taken into consideration', she's saying 'they really will listen to what you're saying about your child as well'. But it frightened me though, it sounded very serious and I felt, I remember thinking 'is this going to affect us for the rest of his life?' "

Pat's recollections of the statementing process were hazy and as parents their role in the process had been reactive.

"I think she was about two and a half when she went into the nursery. We found out about her disability when she was fifteen/sixteen months old and she was in the CDU for a while. It was just by chance really. A friend of my mothers was a teacher at Cliff school, She said 'we're having an open day, why don't you come down and have a look?' We did, we went back to the CDU and said 'we really want our daughter to start now in the nursery'

and she was there from age two and a half to eleven when she left to go the secondary school. So I can't honestly remember when the first statement was. I think I was just told by school. I was sent a letter saying that this would be happening every year. She'd have a regular review and we just went into school and discussed it with the staff at the various support services and what have you. I can't remember that far back as to how we found out about it. Actually, I think it's very useful, I think it serves a purpose. I think that people are there who genuinely want to help and try to improve things. In theory everybody who is connected with the child is there and everybody presents a written statement beforehand for us to read and digest, make notes on, go along to the meetings and comment on the end of the meeting. At the end of the meeting we're asked if we're happy on the provision made for the child, so I do feel we have got some way of complaining."

Adele spoke of the impersonality of the process.

"it's not so bad. I mean, you sit in a room with people who are supposedly experts in the field and they're talking about something not even related to your child. To me the way it comes across you wonder if you're in the wrong room, you know, you've got this child, to you he's yours. He was statemented as having learning difficulties and he was sent to Peak school and that went wonderfully well for about twelve months and then nothing was happening, he'd had confidence smashed out of him at the other school. It was awful. He was picking things up, then it went stale. It was a nightmare of a time because all of a sudden this child apparently had all these complex difficulties."

Debbie had initially been guided by the CDU but she spoke forcibly about her later experiences as she struggled to obtain what she and her husband considered to be the best school for Alec.

"We were guided by the CDU to the regional language unit attached to a mainstream primary school which we were advised 'if you are offered a place, take it, it could make all the difference'. So we went through the usual channels of assessment and Alec was offered a place down there. He was three and a quarter when he started there. During the time he spent there, in fact, his language deteriorated rather than improved. The unit only took children until school age and Alec had made some progress there, he had started to read so I looked to then moving him to our local primary school and the staff at the unit backed this up and said 'yes, it would be an appropriate move and Alec could cope'. So visits were arranged for the head teacher and the special needs to go and assess Alec. The upshot was that I was told, not voluntarily, I had to go to the school and say 'did you go, what is your finding?' I was told quite bluntly 'we won't touch your son with a bargepole' and those are her words. It distressed me no end. I asked why and she said 'he's too severe for us, it's not fair to subject other children to the likes of your son'. So, exit Mum from the school in floods of tears with young baby in tow. I went straight round to the language unit because I felt I had been led up the garden path by them, rightly or wrongly I feel that the staff that are working with the child at the time must know what route that child is going to ultimately go down, and they had led me to believe that it was a mechanical process that we were going through. I felt lied to and cheated so I withdrew Alec from school at that point. Literally took him out of school and kept him at home with me while I calmed down. Eventually I did go back under sufferance and we then realised that the statementing procedure was going to have to be gone through. That was all kicked into action, but he was going to need something other than mainstream.

It was sort of thrown in our way. 'Your child will have to be statemented' and we said 'what's that?' That was at the language unit. 'Well, reports have to be made and he has to be assessed to see what provision he needs'. And then we found out that we actually started the statementing procedure long before even when we were aware of it and Alec had actually been seen by an edpsyhc. 'Has he, when was it?' 'Oh, a few months ago.' And we didn't even know and it was still unknown territory to us, we didn't realise anything had happened, we didn't realise our son had been seen by an expert. No information at all. When the word came our way I started to research it myself, find out about it, get in touch with the Town Hall, requested the booklet that they do issue. We read the book, my husband and I, cover to cover and realised the implications that as parents, if we didn't keep our wits about us and keep on the ball every step of the way, our son could be placed wherever they fancy. If that statement is written the way they want it and not the way we want it. So we had to get aggressive at this point, mainly myself because my husband is out at work and he catches up in the evening. Our first point of action when knowing that he was going and these doctors and psychologists were all going to have a poke and a prod at Alec and write about him and know that the end product will be that 'we recommend that he is placed at ....' So we thought at that point 'let's beat them at their own game and go around every school with a unit of some sort, lets draw up our own master plan, and we had our own sort of hit list; things that we had prioritised and we went round every one that was registered in the booklet, and we assessed them all. I read up about it then I wouldn't sit there and look stupid because they throw these words at you. I did not like it. I felt that somebody else was totally taking control of my child and his life. He's our child. If anybody's going to take control it's us. We know what he needs."

[NB Debbie's 'Hit List' can be seen as Appendix F]

John spoke of his struggle to get Edward statemented and, subsequently, into the school of his choice.

> "The school said that they would not be able to take Edward on and that's when we really started worrying, really. It went on for twelve months, something like that, and we seemed to be passed from the occupational therapist to the physiotherapist, to the speech therapist and back on to the occupational therapist and back to Dr Sure, and we saw a couple of psychologists and then we were passed on to somebody else, passed on to somebody else.... It seemed to go on forever and we seemed to be going round in circles. Me and my wife were getting really, really, fed up. We seemed to be getting nowhere and it wasn't until, we were watching Kilroy and he had a thing on in the morning with parents with difficult children and there was one parent there, he was saying what his son was like. It turned out at the end of the programme that his son was autistic. I'd heard the word autistic but I didn't know what it was. The family mentioned that he could be autistic and I went berserk. I always thought autism was a mentally, you know, a mental or physically handicapped child and that's what came into my head when autism was mentioned. So I started reading up, got some books from the library. I read a book by a women who was autistic when she was younger and got better if you know what I mean. It was a brilliant book. I can't remember the woman's name but it was an absolutely fantastic book. We actually had the final statementing where we all had to go up and sit in front of everybody and they said what they thought was right for Edward. They said there was definitely something wrong with Edward but they didn't know what it was. I blew then and said 'Look, I've got one question to ask, and I want a truthful answer. Is Edward autistic?' They were like gobsmacked and Dr

> Sure said 'No, he isn't'. She then said that he showed slight tendencies and I said 'That is rubbish. He either is, or he isn't.' She could see I was getting more upset, or getting furious actually 'cause Edward was supposed to be starting school in September and this was like in May of that year. So I said to Dr Sure 'Look, well I think he is anyway'. So she said 'Right, what we'll do is, we'll send him to Mr Gras. Mr Gras works at Port Hospital and he is a psychiatrist. A psychiatrist is the only guy who can diagnose that Edward is autistic.' So I says 'Right, fair enough, so how long is that going to take?' They told me nine months. That's no good, he starts school in September so I asked them to phone him up and ask if I could see him in private. I got an appointment two days later but I paid two hundred pounds to see him and it was the best two hundred pounds I've ever spent. He was brilliant. We went back then to Dr Sure, she said 'Yep, I've spoken to Mr Gras, I didn't really want to tell you that he's autistic'. She didn't have the bottle or want to carry the can for it and she bottled out."

Most parents did not appear to feel that the process surrounding the identification of their child's educational needs fulfilled the stated aims. Nor did they generally feel a sense of satisfaction with the process. The Northern parents' responses on the choices available to them once it was acknowledged that their child should attend a special school, point to limited choice with few options open to them. How they approached and dealt with that choice will be considered in the next section.

CHOICE OF SCHOOL

The Education Reform Act 1988 gave parents the scope to choose the schools their children will attend. In addition to tables showing examination

results schools are required to produce various statements about their aims and objectives. One of these is a requirement under the Disability Discrimination Act 1996 requiring schools to publish information on the accessibility of their school, and strategies for accommodating disabled students. With all these requirements parents have, in theory, never been in a better position to make an informed choice about their child's education. But did the Northern parents find that they were able to make such an informed choice? The following accounts will help to answer that question.

Fiona spoke of there being little choice.

> "There wasn't really that much to choose from anyway as far as Autism goes. It was a bit of a battle really because the education authority said I had to send her to Mount. I went to visit and I knew straight away that it wasn't the right place. it had children with all disabilities. I knew because of the way she behaved when other children were around her that she couldn't cope in a class of thirty. When I went to Ash and saw that there were only two and three and four in a class I knew that that was the place that she should go. They insisted she went to Mount but I stuck to my guns."

Mohammed found that he had no option when it came to selecting a school for Jamil.

> "Well, I went to go and have a look at it. It is a good school. I don't argue with that but where special schools are concerned it's entirely different. They don't teach what secondary schools do. They arranged for me to go and look at one and it was all right, you know, and it was a local school near to our house so there was no options then. That was the only school provided."

Helen had always attended some form of special provision so Ruth felt that choice had been exercised by choosing to retain the status quo.

"We chose basically to stay the way we have done just because of the way she is. She wanted to stay with her friends and basically that has been the main structure of Helen's education because she wanted it that way. She has chosen that in quite a thoughtful way. Also the school was brilliant. They listened to us basically and they were backing us. Really we were going for what Helen wanted and that's the way we've gone."

Adele, too, had little choice:

. "There was Ash or a residential place, and that was it. That is awful. The fact that there is only one choice."

Margaret had been content with existing provision so had not attempted to seek alternatives:

"Actually, before, we didn't really know the other schools round about. I suppose as we were happy where we were we didn't ask questions whether there were alternative schools for her to go to so we never went round any, you know, but the college told us about residential schools and the other schools."

Angela spoke of the negative way in which choosing mainstream was presented to her by her local education authority.

"There wasn't a great deal of choice. The option was 'if you want him to go into mainstream education, that's fine, but we are not going to come up with the other things that you want'. That's basically what it came down to. Alan's condition being as it is he needs those other things. Weighing it all up, weighing up the fact that Alan is integrated in a certain way in that he is in his family, he is in the community, he goes everywhere we go, there are able bodied kids going into the school, he does mix and meet with able bodied kids as much as I can help him to do that."

Susan based her satisfaction with the degree of choice available on her happiness with Sara's school.

> "I would say 'yes' because I'm quite happy with the school. Well obviously the support you get is very good. It was four to five schools and I don't think it's any good having a list of twenty, personally because you could, I think, get lost anyway, wouldn't you, half way through?"

A lack of information was a feature in Sandra's response.

> "Well, with Mount [the first school] I didn't have any choice. I was told that that's all that was available and I was quite young at the time and didn't know the ins and outs of it all, so I didn't question and then when he went to secondary school I had a look round all the different schools and I felt that one was the best for him."

Debbie considered that she had not been presented with a real choice.

> "Well, there was no other choice, no, there was nothing other than travelling even further. We did visit a school in the city which did cater for autistic children but it did not meet our social needs, the distance again, the atmosphere of the school was not the same as Ash, barbed wire fences and things like that, which I can understand, perhaps the area it's in, which was another consideration for us because of his dad's occupation, we've got to be very careful where your son goes to school. His dad is a police officer and if he's been working a particular area with parents or whatever, then Alec is a ready target. We have to protect him. It may never happen but it may happen every day, every week, and he cannot protect himself so it's something we've got to be aware of. Things like statementing don't take personal accounts into consideration, but surely a parent's needs are more than just education, it's the physical, the emotional, the social, the whole lot.

What's the word? Holistic. That's exactly it. We said within six weeks with Alec being at Ash his whole being had changed."

The above views are those of the Northern parents whose children were sixteen or under. Experiences were different when it came to post sixteen.

Janet had found the move from secondary to tertiary education problematic.

"Oh, terrible process. Well, we were told from the secondary school to have a look round at all the different schools and if we thought, or if my husband and I thought we wanted him to go to the college then it was funded and then they explained how difficult the process was. But we just looked round with an open mind. So I visited quite a lot of the colleges and I think it was the Aspen school where they can go until they're nineteen. But I still felt that the college was the best place for him but I think the process is terrible. I really do. You're left completely in the dark. I mean it's all right teachers trying to say 'oh well. I can't foresee a problem. I think he would get in' but you're left until basically the last minute 'til the last four weeks. I think I got to find out about four or five weeks before Simon actually went and, I mean, it's quite an emotional time and, to me, I think the service could be improved greatly. The headmistress at the time was trying to be very non-committal really because, I suppose, she didn't want any comeback from me if he didn't get in. She's saying she has to be impartial and you have to look round all the other alternatives as well. She was trying to be very supportive but, you know, I mean, anytime I wanted to talk to her she'd be there to talk to, but I felt she couldn't give me the information I wanted to know. I just wanted to know, you know, was my son able to go to that college. I mean, she did say she would help fight the case if he didn't get in, but it's just very difficult not knowing."

On the evidence of the above, parents had mixed experiences when it came to choosing schools for their disabled child. Some had identified a specific school which they felt met their child's needs and then argued with their education authority to persuade them to fund the place. Some were given no choice and were told that a particular school was the only one available. Some took it upon themselves to identify and visit all the schools which they considered might meet their personal selection criteria. There were also some who were given information and choice by their education authorities, and there were those who did not want choice because they were content with the quality provided by the school their child attended.

Two of the issues arising during discussions about the special schools and choice were the balance between the provision of care and para-medical services and the pursuit of educational goals and, whether or not, parents would prefer their child to attend a mainstream school. The Northern parents' observations on these two issues are dealt with in the next section.

MAINSTREAM OR SPECIAL SCHOOL - ISSUES FOR PARENTS.

Parents commented on the difference between special schools and mainstream and, whilst their views on why they had chosen a special school were recounted above, aspects arising from their child's actual attendance at a special school arose subsequently. These tended to focus on parents' lack of faith in the ability of government to match the political rhetoric of inclusion with resources, and the quality of para-medical services which would not be available in sufficient volume if their child was attending a mainstream school. The following accounts will highlight those feelings.

Although, when David was younger, Helen had given some thought to him attending a mainstream school, she was in no doubt that special school had been the correct choice.

> "I mean, I think it's wonderful to be able to give out of school opportunities and all that sort of thing, but David is also learning to his best ability, to his level. It would be different if he was highly intelligent and could read and write and do exams, but he can't, so for David it's perfect. I did at first think integration might be a good idea, but not now. David would be completely lost. I don't think it would work for him at all. He would be out of his depth. I think special schools are fantastic, they've got such facilities, they get such opportunities. There are such levels of staff. I don't think you can beat it."

Sheila felt that James would be unable to cope in a mainstream school but that if he had been able to attend from age five then matters would be different

> "If he could speak then I would have been more comfortable because he can't walk and he's no speech, and he gets a bit, you know if it's loads of children running around, he tends to flinch a bit. If it was a small school - but he couldn't cope where Mary [sister] is now. Maybe if he had started from five, but to take him out now, he's too used to it. If they mixed them right through, then that would be great, children would get used to children with disabilities and it wouldn't be a staring curiosity, kind of thing. I think they do a very good job given the limitations on them. The classes are about six and there is a teacher and two helpers, which is quite good. I would like more speech therapy but that's not education, it's health. I have complained about that in the past but there just aren't enough speech therapists. He gets used to

them and they leave. They move on to other things and then another one comes along with new symbols and new charts. He gets used to them and then they move on. I would like much more on vocalising and less on other methods of communication."

Ruth spoke of Helen as having become more independent so the need for care had lessened. Helen was now in her late teens and had always attended special schools.

"I don't think the care side matters so much to her as now she is quite independent. She can, she is not in a wheelchair, but she topples over at the drop of a hat. They sort of give her a brilliant, how can I put it? I've just been to her review and I'm very pleased the way it has been going. They want to give her social contact as well as educational needs. So she's got quite a varied, her menu if you like, her daily routine is all quite varied. They are very caring people.

I think, if we are looking at it now, I mean Helen is not looking at that now, she is looking at in twelve months time going into a residential college. But if things could be catered for her to carry on with her education and stay within the home environment, then I'm for it. I mean, mainstream, yes, if she can cope with it, because she does an odd class with a mainstream college now. It would be nice."

Adele had wanted Tony to attend a mainstream school but implied that the amount of therapy he received at Ash would be unavailable elsewhere.

"That is what I wanted. This place is wonderful for Tony. I mean my ideal was a set-up in mainstream which wasn't ever going to come off. I think the speech therapy is absolutely untrue and out of this world. You have three sessions a week which is definitely not available anywhere else. Now, that side of it is brilliant. The

only thing is that it's happening too late. It's at the wrong age. It should have been done beforehand and now not as much can be done for him. It's already been decided, well, he's been diagnosed, not written down anywhere because we don't label anymore. No, that's not on his statement. He's still got moderate learning difficulties on his statement."

Andrew and Susan had considered mainstream education for Sara but felt that she would not, at the present time, benefit from mainstream.

"We would have done but at this moment we don't feel that she would benefit from mainstream whatever the level of support. It's just the everyday physical effort and the amount of children in a class, that many and that busy, it's too much for her. And then physically, if she get stressed, which is what it was like at George Lodge [previous mainstream primary school]. She was stressed with her lessons, the lessons were too much for her and even though in George Lodge it was thirty children in the class, and they had like a teacher and a helper, and if, say, six children would have some sort of disability, it's just too much for her, you see."

Sandra was clear that Martin benefited from attending a special school because he gained satisfaction and self confidence from being with other children with impairments.

"Basically I sound prejudiced now but I think he excels around other people that have handicaps, you know, and he likes to be helpful and helps the ones that can't move about like he can and, you know, plus, because of his facial deformities I think he would get a lot of prejudice off other children. Whereas he's just classed as normal in the college he's at now. He did, and he was, able to do so many more things, you know, and things that I thought were impossible for him to do."

Debbie echoed the views of a number of parents when she talked about the experience Alex had had of mainstream and how she thought he was benefiting from the close attention he got at Ash.

> "I think he gets a lot of speech therapy in that he gets full sessions of an hour and they adapt the sessions. They are very on the ball and it's working. He hated the sound of his own voice but now he sings at the top of his voice. We are happy with the speech therapy. As far as the education goes, Alec is able, he's got the ability and the staff are working at a way to get into actually doing it. He can do add ups and sums. He has rekindled an interest in reading. He is holding a pencil. His academic skills are coming along and they are academic skills that are relevant to Alec. If Alec could have coped with it. You see there were so many children. Always when he was at mainstream he was in a unit attached. He was always with groups of about ten but come lunch-times he was thrown into a dining room with two hundred children. He couldn't handle this. He was being bullied. I know because I caught two boys bullying him. They were totally oblivious to him. I was being called into school and being told 'Alec's been pushing children in the playground. We don't like it'. I had watched from my car and seen children playing in the playground and it was Alec's way of communicating. He did not have the language or the skills or an understanding of the natural barriers so he would react and behave inappropriately. Next thing I'd be called into school."

Mohammed thought that education was inevitably sacrificed to accommodate care needs.

> "I think that education might suffer. But they need to do it because he can't walk. He does need physiotherapy and I know it is a good idea with both in one place, the school side and the physiotherapy.

He's thinking of going to a normal college. He doesn't wanna go to one of them special colleges but we're going to look at them. He's thinking of going into computers and I think if they can provide the facilities then we'll send him to a normal college."

Janice was unequivocal in her praise of service provided by Beech School.

"It's absolutely excellent. You've got to go into the school to see the whole thing working and see the dedication of the staff. This is a very small set up with highly trained people, high ratio of staff to children and it is a very intimate set-up, small, everybody knows everybody else."

Fay and James had given the option of mainstream education some thought. However, they had concluded that political rhetoric was not matched by resources. Not only did they feel that resources would be inadequate, but that current attitudes amongst school staff would need to completely change if disabled children were to be fully included without detriment to their well-being.

Fay. "We had this debate."

James. "I think all of us would prefer mainstream education but we must be honest, clearly that isn't an option with Louise."

Fay. "It's not an option when we have the government looking at the education of disabled children. It would not just affect the children, it would be professionals who would be required to make a quantum shift."

James. "But within the statement that we just made I think we actually tried to make sure that the school would be one that integrates Louise into the totality of the school because I think we have come across one or two schools in our search where Louise would be isolated."

Alice had no doubt that special education was the right choice and expressed cynicism about mainstream education.

> "No. I don't believe in integration. I think it's a cheap way to educate kids with special needs. Linda is sixteen, she can barely read and write. The mainstream school is more geared to the teaching of English and Maths and so on but the special schools are more geared to computing. She can use all the computing and stuff like that because they are all taught with this these days but she can't read. She can recognise words and she doesn't understand money at all. I don't think they push them enough. They let them do whatever suits them to do. I mean Linda is quite capable of reading better than she does read but she has not been pushed enough. A typical day is probably an hour and a half at the most of actual work, and the rest of the time is taken up with doing practical things. It's very difficult really because she enjoys doing those things but she seems to go out more and do more things outside than a normal school would do."

Janet expressed pessimism about the chance of inclusion succeeding.

> "I don't think it's going to work in the present climate we have about disabilities and the way mainstream schools are at present. There needs to be a whole change of attitude and bring in a whole generation of new teachers and teach them about special needs because it'd need to be a part of their curriculum. You'd need to change the way the whole world feels about disability but it could be done and, yes, it would have been ideal. He'd have had a broader curriculum and possibly a lot of the children might aim a bit higher and do a bit more than they do because they're living in a cocooned environment in special needs and they're not encouraged to make their own decisions and we don't encourage them frankly. The overriding thing as a parent is to protect your

child and leave it up to other people to sort out the other bits. There were long periods where we had no speech therapy, no physiotherapy, and with CP [cerebral palsy] children you have to keep reinforcing things, especially speech therapy, and you could just see him physically deteriorating without this input. It's quite difficult because, I mean, their needs are diverse, they need both input from education and proper care and everything like that. I think the college has just about got it right."

It is evident that many of the parents feel that there are positive gains to be had from attending a mainstream school, but that the negative aspects significantly outweigh them. Furthermore, parents did not generally consider a mainstream education to be a possibility because they had either experienced it failing to meet their child's needs, or could not envisage that there would be sufficient support available for their daughter or son.

These views tended to correspond with the reasons given for choosing special education inasmuch as small class sizes and smaller pupil populations created an environment in which parents felt their child was safer and more secure.

Parents referred in passing to initiatives to include their disabled child in the mainstream. These tended to concentrate on individual initiatives to integrate some children into selected classes within a mainstream school, but this was seen as another aspect of special education rather than a step on the road to full inclusion. That said, there were one or two parents who were anticipating their child attending mainstream colleges. These were, however, colleges within the further education sector and not primary or secondary provision.

SUMMARY

This chapter recounted the results of a series of interviews conducted with a group of twenty four parents, referred to as 'the Northern parents'. All of whom care for their disabled daughter or son at home. The views of the Northern parents were collated under headings, which followed a chronological progression from learning of the impairment, through to expectations for the future and factors relating to the role special schools played in their lives.

Consideration of the Northern parents' responses would suggest that:

1. The level of support available to parents at the time of diagnosing their child's impairment is variable and generally felt to be inadequate. Parents also had a different experience of diagnosis depending on whether their child was born with a readily diagnosed impairment or whether the impairment became apparent later in life.

2. The impact of having a child with an impairment affected both family and personal lives. There was an impact on:

> i. Siblings. Parents felt that the lives of brothers and sisters were affected by limitations on the amount of time they were able to spend on them, as a consequence of the time given to providing care for their disabled sister or brother. Although this was tempered by what some parents felt was the positive experience of having a disabled sister or brother.
>
> ii. On mothers ability to work or pursue personal objectives and their ability to sustain friendships with peers.

iii. On general family life. Caring for a disabled child meant that aspects of family life, such as the capacity to undertake collective leisure activities, could be problematic.

iv. On relationships. A number of parents' commented on a heightened level of tension between themselves and their partners caused by the demands of caring for a disabled child. Several parents also identified the emotional consequences of having a disabled child as being a contributory factor in the breakdown of marriages.

3. Support from statutory bodies, particularly social service departments was considered to be inadequate, variable, and often inappropriate .

4. Support should be available in the form of clear information, particularly about options at key stages in a child's life. Also support to deal with the emotional needs of caring for a disabled child, both at the time of diagnosis and during times of anxiety whilst continuing to care for a disabled child.

5. Parents, particularly mothers, felt that there was an obligation for them to continue to care for their disabled child, and that this was a different expectation than they felt towards their non disabled children. Additionally, it was felt that there was an implied social expectation that parents would continue to provide care for their disabled child into adulthood.

6. There was a gender division in roles and tasks performed by parents. Mothers provided the day-to-day care and attended routine appointments at clinics, doctors, and schools. Fathers became involved for important decisions and attended meetings related to those decisions. Fathers also played a greater part in social activities, particularly when their child was male. A further difference was in the undertaking of personal care tasks, fathers did not attend to the needs of daughters when they matured into teenagers, whereas mothers would continue to care for sons.

7. Parents were pessimistic about the future potential of their disabled child, with many of them believing that opportunities for employment, independent or supported living, and social opportunities were at best limited and, at worst, unattainable.

8. Parents acted as advocates for their disabled child and made decisions on their behalf. Notwithstanding, many parents felt that they were the only people who were either available to do it, or, were the only people in a position to know what their disabled child wanted. Some parents had reservations about continuing to perform this role, but could see no alternative if they were to avoid advantage being taken of their disabled child, or that they would be abused.

9. Special schools and segregated provision was generally seen as providing the only realistic opportunity for their disabled child to receive an appropriate education and necessary therapeutic interventions. This was coupled with an experience of mainstream education, education professionals, and local authority bureaucrats which had been marked by:

i. limited choice

ii. struggles by parents to get what they considered to be the best for their disabled child

iii. poor experiences of mainstream schools, notably teaching staff

iv. pessimism about the ability of schools to deliver inclusive education in the present political climate

However, this somewhat prosaic list of the main conclusions of the Northern parents' accounts struggles to convey the impact of those accounts. Whilst, as mentioned in the introduction, parents choosing a special school are castigated as either heinous villains, denying their disabled child the opportunity to be included in mainstream society by ensuring that they remain

in a state of 'eternal childhood'. Or, as hapless victims of socialisation who are unable to see beyond what is presented to them, and thus inculcated into a mind set which causes them to see their disabled child as being different and, therefore, needing to be educated 'differently'. Neither of these descriptions truly fitted the Northern parents.

It would be true to say that the Northern parents were active in choosing a school and, whilst the choice of some to do nothing may from the outside appear to be an act of compliance, it was evident that parents did make an informed choice about special education. It may be that a proportion saw special schools as safe havens for their children. But this was as a consequence of their experiences at the hands of professional educators and the mainstream education system. There were those whose child had never attended mainstream school. Nevertheless, those parents also had non disabled children attending mainstream schools and, as a consequence of those experiences, they had concluded that mainstream was no place for their disabled child. It was evident that, generally, parents had thought about the consequences of a special education. Most of them would gladly have sent their child to a mainstream school. Many had, indeed, experienced mainstream schools and the experience had left them embittered and wary of the teachers in the mainstream. Their choice had been that their child should receive the best that could be found, and that could not be found in a mainstream setting. That there would be consequences resulting from a segregated education were not denied, but if attending a special school resulted in their child having the chance to develop their abilities to their fullest potential, then they would be better equipped to deal with the world than if they were the object of bullying from fellow students, or oppressed by teachers who considered their child's presence in a mainstream classroom to be detrimental to other, *sic* non disabled, students.

It was clear that the lives of parents caring for a disabled child are a complex matrix of support networks, coping strategies, and systems. The 'twenty five' hour day referred to by one mother sums up the intensity felt by many parents

caring for a disabled child, and it was evident that the special school, for those parents, provides more than the provision of an education for their child. School for the Northern parents formed an integral part of the matrix that comprised their lives. As Debbie said 'Surely parents' needs are more than just education?'. This view might be criticised by inclusionists who would probably argue that education should be for the child, not the parents. But the Northern parents had largely been jettisoned by the education professionals in the mainstream and forced to rely on their own resources to procure the best for their disabled child. Equally, they had received little, or no, support from their social services departments. What services they had received focused on providing respite care or, in the scant instances where there had been an identified social worker, they had provided a degree of personal support for mothers. What was strikingly clear was that the Northern parents had had to sort things out for themselves. Even in the cases when the disabled child had always been in the special school 'system' parents were having to sort out other elements of their lives for themselves. The decision to opt for a special school, or the argument for continuing to sustain their child in one, was based on a measured consideration of the needs of individuals within the family and the family overall. There was a degree of pragmatism stemming from a sceptical view of an education policy, which took the high moral ground of inclusion, yet did not match the rhetoric with practical support in the home, in the community, or in the school. Indeed, far from not considering mainstream education as an option, the Northern parents had generally given it measured consideration with a consensus emerging, which concluded that education was not a discrete process and should, therefore, not be seen in isolation from society in general. Aptly summed up by Janet who made the adroit observation: "You'd have to change the way the whole world feels about disability".

A criticism which could be levelled at special schools and, therefore, by association, at parents choosing a special school; is that they are 'warehousing' disabled children. Thereby parents are liberated, and can go

about their lives, without having to concern themselves with their disabled child. Somewhat perversely, the Northern mothers felt that that was the situation for mothers with a non disabled child at a mainstream school, and that if it was not for the special schools they would not get any time to themselves. The time they did have to themselves was used to recuperate and recharge batteries. Although they did, nevertheless, have to be 'on call' all the time their child was at school in case something 'went wrong' and they were needed. This being the only time during the day when they were not occupied with provided care, as well as running the home for the remainder of the family. A family which many mothers felt guilt about not being able to devote sufficient time to, because of the time taken up by caring for their disabled child. Of course, this is a consequence of the inherent gender imbalance in social roles, and there are many texts which analyse this, however, as with inclusive education, the ideal is far from the reality, and mothers live in the 'real world'. That world has presented them with a situation in which the power of social roles, like disablist attitudes, has created a reality which they have to find a way of accommodating. Special schools provided an element of support which is an encouragement for them to continue, not that they felt there was an option, but the support they received from special school staff was, in most instances, the sole example of any form of support from statutory bodies. Not that it should be assumed that the support received from special schools, compensates fully for the lack of services received from other agencies. Rather it meets some of the emotional needs of parents, particularly of mothers, and provides an element of insulation between the battleground of society and their needs for support services. However, the trap should be avoided of assuming that, if the idyllic situation in which a level of care and support was achieved which met all parents' needs, then the underlying issues around the role of mothers caring for a disabled child, and the ability of mainstream education to include disabled children, would dissolve.

As subsequent discussions will show, the issues around inclusive education will not be resolved by shifts in social policy alone. Nor will the evidence point

to there being any trends which would suggest that the role women perform as primary community carers is likely to change. The complexities associated with the debate on inclusive education will form the substantive content of Chapter 5 whereas, how typical the experiences are, and how parents and mothers of disabled children are viewed, will form the basis for the next chapter. Chapter 4 will, therefore, place the experiences of the Northern parents within the wider contex of existing research and literature.

Chapter 4

DISCUSSION: The Northern parents in context

INTRODUCTION

Parents with a disabled child face a diverse range of difficulties. As the Northern parents demonstrated in the previous chapter many of those difficulties are a cons175equence of the way institutional practices impact on their lives. Practices such as the separation between education, health, and social services, which result in a lack of co-ordination between services and, more to the point, limited and inadequate provision of support to parents caring for a disabled child at home. On the evidence of the accounts provided by the Northern parents this can be seen as a major reason why parents, notably mothers, experience exclusion from a variety of activities outside the home. Those range from limited opportunities to undertake paid work, to restrictions on the ability to access leisure pursuits, such as the cinema or holiday destinations. It was shown that gaps in service provision and social support had, for many of the Northern parents, been ameliorated by the support provided by special schools. It was argued that this went some considerable way to explaining why the Northern parents had selected special schools for their disabled children and continued choosing them as their preferred mode of schooling. However, this was not the whole picture, with many parents citing their experience of mainstream education as the motivating factor which influenced their decision. However, as Chapter 1 cautioned, generalising from the findings of the research should be treated with caution but, nevertheless, it was suggested that there may be similarities between the experiences of the Northern parents and those of other parents of disabled children. That being so, unless the experiences of the Northern

parents are to be seen as an interesting, yet localised, phenomenon, they need to be viewed within the context of existing research and literature on parents with disabled children.

The Northern parents' study identified the complexities one group of parents faced when caring for a disabled daughter or son, and it was argued that to make sense of the choice of a special school, the totality of the experience of caring for a disabled child has to be considered. This is not to imply that a moment of great intellectual insight revealed this. No, the explanation is more prosaic. As explained in earlier discussions, it was revealed in the detail of the survey responses provided by parents, which led to the re-direction of the research. However, whilst the above research identified a wide range of factors impacting on the lives of parents with a disabled child, which often included the subject of special schools, the tendency to view special schools negatively and, therefore, to deal with the subject in terms of 'how can disabled children be included in the mainstream', pervaded. This may be the experience of being a minority, and therefore, feeling the need to justify a chosen position. Or, it may be a consequence of social policy which has, through political statements and public pronouncements, helped to promulgate a vocabulary based on the concept that to be in the 'mainstream' is to be included in society whereas, to be out of the mainstream, for example attending a special school, is to be excluded from the mainstream. Additionally, the disability rights movement and writers on disability, for example, Barnes (1990, 1996), French (1996), Mason (1992), Oliver, (1983, 1987, 1990, 1993, 1996), Oliver and Barnes (1998), Smith (1994), have attacked special education for creating disabled young adults who see themselves as dependent, and unable to contribute to, or participate in, mainstream social activity. One consequence of the dominant position of the above literature and the pervading concept of exclusion is that parents who have chosen special schools do not, on the whole, tend to be heard. This is unfortunate because we do not fully understand, hence this study, why, or how, parents make that choice. Consequently, if reasons for the choice are

not understood then the effect on parents, and mothers in particular, of abolishing special schools cannot be gauged.

However, as noted earlier, because the Northern parents developed their thoughts, experiences, and feelings randomly, although staying broadly within the parameters of the interview schedule, their responses were ordered under headings to make common themes more visible and suitable for interpretation. At the same time, by presenting the information in such a way, the illusion that parents see the different aspects of their lives as distinct entities could, potentially, be created. Therefore, to follow that pattern would be to continue to risk creating the illusion of compartmentalisation which could result in the complexities, already highlighted, of the lives of parents caring for a disabled child being masked. Consequently, the main issues raised by the northern parents will provide the foundation for the following discussion, which will locate those key issues within existing literature. This signals the need to understand the significance of particular events in the lives of parents caring for a disabled child, and how those experiences have textured the fabric of their lives, inasmuch as they overtly, and covertly, affect the way in which parents caring for a disabled child interact with the extrinsic world.

That said, the chapter will be structured so that the discussion will, firstly, consider the identification of a child's impairment. The disclosure of a child's impairment is significant in several ways, but it is significant in this context in that it marks the first chronological event in the 'career' of parents caring for a disabled child and, therefore, logically forms a suitable starting point. However, a more telling rationale is that it is because of the significance, that those earliest contacts with professionals in the context of their child's impairment, have on longer term relationships between parents and professionals, that it should be the first area of discussion. That discussion will also consider how parents are viewed in literature on parent/professional relationships. The second area to be covered will be the impact caring for a disabled child has on differing elements of family life, that is, the effect on

siblings and parents' relationship, Because the study indicated that mothers felt obligated to care for their disabled child beyond the time anticipated for a non disabled child, and also that they considered the role they performed for their disabled child was different, there will also be an examination of concepts of motherhood. This will include a consideration of the role performed, largely by mothers, as advocates. Thirdly, the quality and quantity of social support will be featured, along with a look at the relevance and significance of social policy. This component of the chapter will be completed with a consideration of how special schools feature in the web of services, policy, and legislation which have the potential to be brought to bear on the family caring for a disabled child.

DISCLOSING AN IMPAIRMENT AND THE PARENT/PROFESSIONAL RELATIONSHIP

The significance and impact on parents of the identification that their child has an impairment cannot be underestimated. It has been shown to be a distressing experience for parents, but evidence has indicated that the experience can be ameliorated, or exacerbated, by the attitude of medical professionals. Research, Baldwin and Carlisle (1994), Beresford (1994a, 1994b), Glendinning (1983), Quine and Pahl (1985), has established that parents feel that doctors, and other medical personnel, treat the event as a tragedy, with mothers often segregated from other mothers immediately after giving birth. This begins to set in train feelings of isolation which become a recurrent element in the lives of mothers caring for a disabled child. Indeed the relationship between parents of disabled children and professionals is different to that of other parents, and becomes a significant component in their lives. Consequently, the way in which parents feel about the experience of learning of their child's impairment can have long lasting ramifications for their subsequent dealings with professionals. Chamba et al, (1999),

established that if parents felt positively about their relationship with professionals then they were more likely to make full use of support services. On the other hand, if they viewed professionals negatively then they often did not make any use of services. Chamba et al (1999) also established, that for parents whose mother language was not English, the experience of disclosure was made more stressful if there was no interpreter present. Professional attitudes at disclosure can also begin to instil in parents the notion that what has happened to them is a 'tragedy' so that parents almost inevitably view the birth of their disabled child negatively. However, there are some differences for parents who come to suspect at a later date that their child has an impairment and want to know what it is. Gray, (1993:1041), sees this situation as a plight for professionals who have to tread a fine line between telling parents the '*hopeless prognosis*' and '*leaving them with enough hope to carry on*'. So, whenever disclosure takes place the importance of the way the information is imparted, and the subsequent level of support and understanding, is crucial; both for the emotional well being of the parents, at that time, and the long term implications it may have for the way parents view professionals.

Understanding the way in which parents of disabled children relate to professionals is important in a number of aspects. As Chamba et al (1999) identified, it can affect use of services. It may also affect the way in which parents relate to education professionals offering advice on the choice of school. It could have implications for the way in which parents interact with social workers wishing to offer information and advice on how their disabled daughter or son could make the transition into adult living. Consequently, this section will focus on factors which impinge on the interrelationship between parents and professions. The main factors to be considered are:

- Perceptions of when it is best for parents to learn of their baby's impairment.
- Issues surrounding the quality of disclosure.
- Professional attitudes to the birth of a baby with impairments.

- Theorising the implications for parents of the birth of a baby with impairments.
- Social work interventions into the lives of parents with a baby with impairments.
- Conceptualisations of families with a disabled child.

Perceptions of when it is best to learn of a baby's impairment

The way in which the issue of disclosure was spontaneously introduced by most of the Northern parents made it clear that the identification of an impairment was a highly charged emotional time for them, at whatever stage in their child's life this happened. Identification occurred at different times in the early lives of children, some parents being 'left in no doubt' because of the obvious degree of impairment at birth. Whilst others found out about their child's impairment during his/her early years. In addition there were those who came to feel that their child had some form of impairment, and had to push professionals to provide a diagnosis. The Northern parents were clear that they wanted a definite diagnosis as soon as possible. This, they felt, enabled them to begin to deal with the reality that their lives would be different and to set about planning for the future. Whilst the Northern parents were able to look back rationally on that time, they also spoke of how emotionally charged the process was. Whilst the Northern parents emphasised the need to know as soon as possible, the literature contains some qualitative variation on the significance for parents and children, of the time at which the impairment is disclosed or confirmed. Glendinning concluded that it was better if parents knew immediately:

> 'Nevertheless, knowing something of the child's disability right from birth was generally felt to have made it easier to come to terms with.'
>
> (1983: 22)

Glendinning evidently concluded from her research that it was important for parents to 'come to terms' with their child's impairment, so that they could begin the emotional adjustment implied by that term. 'Coming to terms' can be taken to mean the need for parents to adjust to a different identity. An identity that pathologises them as now having an identity which ascribes to them, an experience of parenthood which is different to that of parents of non-disabled children. That is to say 'normal parenthood'. This conveys the message that the child's impairment is an individual problem, a *'disaster'* (Barnes et al 1999:103), and locates the need for adaptation and adjustment firmly with the parents, rather than stressing the need for society to respond by providing appropriate services. It can also be compared with how disabled people are expected to 'accept' their disability, *sic* different and devalued identity. The concept of a 'disabled identity' forms a key element of subsequent discussions so it will receive detailed attention in later chapters.

Fitton, adopting a different rationale, focusing more on the child's needs than on those of the parents, suggests that there are advantages if the timing of disclosure comes later in the child's development:

> 'I have talked to many parents who have received the news about their child in many different circumstances. We have discussed what is the most difficult to cope with: knowing there are disabilities at birth: learning later after you realise something is wrong: or having a 'normal' child who develops a viral illness or has a road traffic accident, and as a result becomes disabled. The way in which parents are told, where the situation is apparent immediately after the birth, must influence how well the baby is accepted. Those of us who learned at a later stage of the disabilities had at least built up a relationship with our child and were less likely to reject them. It is a very individual matter - too important to be left to the chance sensitivities of individual doctors.' (1994: 6)

The experience of the Northern parents was also one of individuality. Both in the way in which they received the information and the stage at which they received it. The Northern parents made particular reference to the way in

which they were treated by doctors and other professionals at the time when their child's impairment was disclosed or confirmed. The event generally being denoted by a lack of sensitivity on the part of doctors. Although there were exceptions, those tending to be at specialised childrens' hospitals where, it may be assumed, doctors have more experience in dealing with parents in this situation. Nonetheless, other evidence does point to Fitton being correct to suggest that it is '*too important to be left to the chance sensitivities of individual doctors.*' (Ibid). However, Fitton does not contradict Glendinning's view that parents need to know so that they can get on with adjusting to their new set of circumstances, merely at what point this should commence. However, the way in which the impairment is disclosed potentially has longer lasting implications for parents' relationship with professionals.

Disclosing an impairment to parents

At whatever point a child's impairment is disclosed to the parents, the issue is one of how that is done so that parents receive as positive a feeling as possible. However, the notion that having a disabled child can be a positive experience is in contradiction to much of the literature spanning three decades. Hewitt and Newson (1970) conducted a study of children with cerebral palsy, living at home, and the following indicates the air of negativity that pervades the disclosure that a child has an impairment:

> 'The majority of babies attending the out-patient clinics for observation in these circumstances [birth weight under 5 lb] will progress and develop normally, none the worse for having had a stormy passage into the world. Some will be less fortunate and sooner or later will begin to show signs that all is not well with them.' (:29)

It could be anticipated that parents would expect to be treated sympathetically at this time. Doctors have historically held a position of trust in British society and are seen as having a fiduciary responsibility towards patients.

Additionally the medical profession has a strong belief in professional ethics. Bury sees this as translating into the 'doctor/patient relationship' which he explains thus:

> 'In fact, while the term 'doctor - patient relationship' has widespread currency, it probably emerged originally from medical circles referring to the claim of doctors to have a special place in the health care system and thus a special 'relationship' with the patient. Put this way, the term seems more ideological than descriptive, rendering clinical judgement and medical claims over the patient benign and conveying a 'medico-centric' image of trust and public acceptability.' (1997:77)

On the evidence of the Northern parents their 'trust' was not always reciprocated with frankness, and could be said to be characterised by 'benign' paternalism.

The expectation by patients that doctors will be sympathetic and sensitive is seen by Gray as being unrealistic. In a study of parents of children with autism he identified contrasting emotional responses between parents and clinicians:

> 'Parents and medical personnel also usually differ in regard to the emotional significance of the diagnosis For parents to have the child diagnosed as having a serious chronic illness is often emotionally devastating. They typically experience strong guilt feelings and are often very concerned about the aetiology of their child's illness and their own role in its onset. By contrast, it is unlikely that medical treatment personnel will experience the same emotional disturbance as parents. Although they may have difficulties they are experienced in such encounters and 'distance' themselves from the situation professionally. The literature on the personal accounts of parents of children with chronic illnesses commonly reports that parents perceive the professional distance of medical treatment personnel as lacking in empathy.' (1993:1038)

This did not accord exactly with the Northern parents. Their expectation was that doctors would give them information on the diagnosis and a clear prognosis. Empathy either as a term or an implied expectation was not apparent. There was clear identification of a need for emotional support but it was anticipated that that should come from another source, that is, a non medical source. Quinn asserts that doctors do not have the necessary skills to deal with the emotional impact felt by parents when learning that their child has an impairment. She points to other sources of aid:

> 'Most physicians do not have the training to deal with the parents feelings, concerns, and fears, nor do they have time to repeat information or to express it in different formats to ensure that the parents understand. Working with the parents to interpret the physician's comments is an important role for the social worker or other professional.' (1998:2)

This was the view of many of the Northern parents who commented that they would have benefited from 'some form of counselling'. This introduces the idea that parents consider there to be a role for professionals to play in their lives and is an early indication of the value parents place on the availability of emotional support. However, the perception of need expressed by parents collides with the way in which professionals theorise parents with a disabled child. The need for, and benefit of, social work intervention is developed by Middleton, who also highlights the medicalisation of disability, as being a key feature in how the identification of an impairment fits into society's ideological perceptions of impairment:

> 'Thus disability has become a medical issue first and foremost. It is commonly defined, diagnosed, and conceptualised as tragic, a mother giving birth to a child with an obvious impairment will probably be moved to a side ward. Many disabling conditions are diagnosed at or before birth or in the first year of life, and are managed from hospital paediatric departments. A great deal of thought and care now goes into the task of 'breaking the news' but it still relies very much on the qualities of individual doctors. The tendency to conceptualise it as a single event rather than a process can

> lead to excessive shock for parents as well as putting pressure on doctors to make predictions which are beyond their current knowledge.' (1999:35)

Middleton's comments come as part of a study she completed with a group of disabled students who were recounting their experiences of disability. Middleton is putting into context the experience their parents would have had. The earlier part of her views are closer to the experience of those Northern parents whose child was born with impairments and, whilst the latter part supports earlier explanations linking the quality of the 'news breaking' with individual doctors qualities of communication, there was little in the experience of the Northern parents to suggest that 'a great deal of thought' had gone into how the news was broken to them. One reason for this might be that the possibility of a mother giving birth to a baby with an impairment is absent from the discourse of motherhood and, therefore, health professionals appear to have no preparation for dealing with the event.

Professional attitudes to impairment.

A possible explanation for the negative way professionals deal with the disclosure of a baby's impairment could be located in how the possibility that a baby could be born with an impairment is approached by professionals during pregnancy. The disability rights movement has been vocal in it's criticism of how the medical profession presents testing during pregnancy as a way of establishing whether or not a woman should have an abortion. *"If there is something wrong with the baby, we just get rid of it".* Attributed to a consultant obstetrician (Amazons, June, 1997:1) The strong message, it is argued, being given, is that to knowingly give birth to a baby with a predicted impairment is irrational, so the professional attitude is biased in favour of a termination. So, a mother deciding not to follow that course of action has to be particularly strong minded to resist the dominant ideology of the ante-natal environment. The pervading ethos of 'the bouncing healthy baby' as being the measure of a successful pregnancy and, implicit in that discourse, a

perfect mother, has the consequence that mothers and, to a lesser extent, fathers, are theorised as suffering a loss when disclosure is made. The absence of an acknowledgement that there is the potential for a baby to have an impairment is reflected in publications on pregnancy and motherhood. Such publications devote very little space to considerations of the possibility that a baby may have an impairment so the association of 'perfection' with 'normality' receives further reinforcement. It can be assumed that pregnant women reading such publications, when allied with wider social attitudes on disability, will fear that their baby may have an impairment and assume the responsibility for ensuring that they do all they can to ensure that this will not happen. Gregory (1991), found this to be the case when she surveyed books on pregnancy:

> 'While the basic theme here is that there is an implicit message that it is the mother's responsibility to take all necessary steps to avoid it, with the corollary that if anything does go wrong the mother may feel somehow to blame.' (:124)

Not surprisingly the common view that having a baby with an impairment has psychological consequences for the mother and, with less emphasis, the father extends into the baby's childhood and beyond.

There was some evidence to support this from the Northern parents, with several mothers commenting on their feelings. Most mothers did not refer to their feelings specifically but tended to talk in terms of the 'loss' as being a life change, inasmuch as they then saw themselves as having to forego personal aims to care for their child. There were also examples of mothers talking of how feelings they had experienced at the time of giving birth, that is guilt and fear, as returning whenever the future became uncertain. Uncertainties being defined as not knowing what was going to happen following key stages in the life of their child. Conceptualising the birth of a baby with an impairment as a loss and, therefore, theorising the emotional impact on the parents within a 'loss model' is a recurrent theme in theories associated with parenting a

disabled child, as illustrated by Cunningham and Sloper (1978:8) *'It is as if the baby they [parents] had hoped for and planned for was dead.'* And so it is that at the time of either giving birth or when the presence of a significant impairment is disclosed, that a range of theories have been developed to explain the emotions experienced by parents.

Theorising the birth of a disabled child

Theorising is a key element in professional training and practice and fulfils the perceived need by professionals to understand what parents 'must' be feeling in order to help them. The perception that there is a theoretical explanation for the way parents' feel, and a professional ethos that implies that this needs to be understood by qualified workers, has far reaching consequences for the way in which relationships form between professionals and parents. As mentioned above notions of 'loss' and the view that giving birth to a baby with an impairment is a 'tragedy' strongly influences professional thinking. Although Russell (1993) stresses the role social work can perform by providing adequate support so that the experience becomes 'positive' and 'enriching'. However, it is approaches linked to the former, rather than the latter, which feature strongly in professional literature and are, therefore, more likely to be a truer representation of professional thinking and attitudes:

> 'Olshansky (1962, 1966), a commonly cited theorist, referred to the experience of parents of mentally retarded children as chronic sorrow in which grief over loss of the ideal child was thought to be carried throughout life by the family.'
>
> 'like Olshansky, Solnit and Stark (1961) were psychoanalysts who considered parents' reactions to the birth of a handicapped child to be severe grief over the loss of the expected ideal child. Solnit and Stark differ from Olshansky in that they felt that this grief can and should be resolved.' Flagg-Williams (1991:239)

These were the dominant views through the 1960s, 1970's, and into the 1980's, which is commensurate with a growth in psychotherapeutic interventions in general. This one dimensional approach is paralleled by approaches emanating from the work on bereavement by, for example Kubler-Ross (1970, 1975), which saw the emotional process surrounding and following the birth, or confirmation of impairment, as falling into three stages. Stage models, as they became known, varied to some extent but largely saw the process as following a pattern of:

1. Shock and denial.

2. Reaction. Including such feelings as; shame, ambivalence, anger, hopelessness, and one which permeates professional approaches, guilt.

3. Resolution. Whereby the parents attain a state of 'coping'.

Other theories have evolved, such as those linking feelings to stress which see the birth of an impaired baby, or disclosure of a baby's impairment, as a 'crisis'.

It is at this point that theories appear to generalise from being explanations of emotional states at the time of disclosure, to explanations of how parents and families react and behave over time. However, such theories do not stop at explaining the emotional and psychological impact associated with parents finding out that their child has an impairment, but continue to be used to theorise parents thereafter. Read puts forward the view that the 'pathologising' of parents with a disabled child has significance in professional fields. Referring to a quotation from Stigen (1976) she comments:

> 'The material Stigen came across was probably not untypical of a strong tradition which has existed in post-war professional literature on parents experiences and needs. Until relatively recently, a very great deal of the literature on families concentrated on personal and psychological variables, and often deviant ones at that.' (1985:17)

The consequences of such theoretical explanations are that if families are seen as 'sick' they can, therefore, be cured. The medicalisation of the impairment, *ergo* parents, again asserts itself and bestows on the professional the authority to administer a 'cure'. As the family will be emotionally and psychologically frail then the medicine to prescribe is therapeutic intervention. This would be in the form of counselling or even psychotherapy, or, if there were social work involvement, a likely approach would be psychodynamic casework. This being an approach which sees the family as a dynamic whole which can be made to function effectively, rather than operating dysfunctionally, which is concomitant with the 'sick' model. The social work role would, therefore, be to work on the dynamics operating within the family in order to stimulate change and a state of equilibrium. As with the previous model the danger for professionals is that they will automatically pathologise the family as sick and think in terms of therapeutic intervention only. Whereas, as Anderson and Spain point out:

> 'The great majority do not require help of the psychiatric or case-work type. They simply need information, practical advice or assistance, and encouragement to help overcome their natural feelings of incompetence or inadequacy when faced with a problem of this magnitude.' (1977:89)

On the one hand this quotation exhibits an appreciation of the risks of pathologising parents, but on the other hand slips back into medicalising impairment by referring to having a disabled child as being a 'problem', and as a consequence parents will have 'natural feelings of incompetence and inadequacy'.

There were certainly echoes of Anderson and Spain's analysis whereby a dominant view expressed by the Northern parents was the need for information. Thereby exposing the difference between professional perceptions relating to psychological need and parents' desire for practical assistance. Furthermore, disempowerment as a consequence of professionals talking in 'jargon' or not taking account of their views was how

the Northern parents perceived many of their interactions with professionals. Professional 'attitudes' and the use of jargon were most strikingly in evidence for the Northern parents around the special educational needs statementing process. Parents frequently told of not understanding what the process entailed, or why it was necessary. It would perhaps be more accurate to describe their feelings as frustration and anger at the way professionals endeavoured to exclude them at key stages, This was done not only, in some instances by physically ignoring or avoiding them, but also by obscuring proceedings in a bureaucratic haze of policy and procedure. Generally the Northern parents had learned to deal with this either by 'learning the language' or by refusing to be sidelined. Whilst this had enabled them to become 'experts' in their child's impairment, and to feel confident in their negotiations with doctors, it had the consequence of them assimilating the medical model of disability. Whether this was a factor in a common view of disabled children as being too frail to cope in mainstream education can only be a tentative conclusion. Notwithstanding, given the power of socialising factors, such a conclusion does have substance. Accepting the continued prevalence of the 'loss' approach might be taken to imply that professionals would be trained in techniques considered to be appropriate to support parents, and that therapeutic support would be available to parents. But, as the Northern parents testified, this was not the case.

It is generally accepted that a major source of support for parents caring for a disabled child at home will be provided, or co-ordinated , by the local authority social services department. This is a reasonable assumption given the duties assigned to social services under the Children Act 1989 , and other legislation discussed below, so the discussion will move on to consider the nature of social work intervention in the lives of parents caring for a disabled child.

Social work intervention in the lives of parents caring for a disabled child

Some consideration was given to the involvement of social services in the lives of the Northern parents and the role they were seen as being able to perform. Interestingly, there was little social work involvement with the Northern parents, so it might be considered surprising that there is, nevertheless, a significant amount of attention given to parents of disabled children in both social work texts and research literature. Much of this focuses on counselling for parents and, as mentioned above, many of the Northern parents highlighted this as a missing need. Whilst on the evidence of the literature, and the views of the Northern parents, the case is, indeed, made for counselling, there are two cautionary notes to bear in mind.

Firstly, Beresford et al (1999:14) warn of the risks of what might be termed 'hindsight bias'. That is to say that care should be exercised when parents who have, with whatever provisos one wishes to add, adjusted to having a disabled child, advocate the need for counselling and describe how it would have benefited them. Caution is needed because in the absence of comparative research, which would, in itself be problematic because of ethical considerations about withholding from one group a service which might, potentially, be beneficial, there is no way of knowing that those parents would have adjusted any differently with counselling than they have without it. Furthermore, those parents who articulate the need for counselling services are likely to be the parents who have achieved higher levels of emotional stability than others who are not being heard. This is not to argue that counselling would not be of benefit, bur rather to stress the need for caution before channelling resources into providing services of untested value.

The second note of caution points to potential dangers in both early social work intervention and the use of medical or social care professionals to counsel parents. The risks are that if counselling is provided to all parents there is potential for parents becoming dependent on the counsellor whilst failing to recognise their own capacity for problem solving and ability to

develop emotional strength and stability. Equally, social workers do not, unless they choose to undertake specialised training, receive training in counselling. Consequently, there is a further danger that social workers may be drawn into providing what they feel is appropriate emotional support, but which may be well-meaning meddling, with unpredictable and potentially harmful consequences for the recipients.

Whilst positive attributes have been given to counselling, Beresford (1994b), Russell (1993), there can be a tendency to professionalise what the Northern parents tended to refer to as 'someone to talk to'. This was a need expressed mothers in the Northern parents' study and also identified by Chamba et al (1999), as a resource parents would welcome. The transmutation of the desire for someone to talk to into a need for professional counselling is an example of what McNight (1981) sees as the domination by professionals of what constitutes 'need', which he argues has created the following situation.

> 'Thus the complex professional remedial tools have come to justify the professional power to define the need - to decide not only the appropriate remedy but the definition of the problem itself.' (:30)

The consensus amongst the Northern parents was for someone who had a degree of experience and knowledge who could support them by listening and offering support at points of crises. The early period when the impairment was identified was one such crisis point but there were others which were less predictable. Consequently, the need for emotional support was felt to be ongoing and needed to be there 'on demand'.

A cautionary note on social work intervention is added by Jones:

> 'While, on the one hand, early intervention can be seen as enabling, in that it ensures appropriate provision for particular children, on the other, it can be seen as a potentially divisive practice separating the 'normal' from the 'special' and leading to dependency.' (1998:44)

Because of low levels of support, Baldwin and Carlisle (1994), Glendinning (1983), Morris (1999a), Read (2000), Yerbury (1997), the risk of early intervention is largely hypothetical for parents of a disabled child. This was also the situation for the Northern parents who had had very little contact with social service departments or social workers. The Northern parents mostly had contact with para-medical professionals so, consequently, they had tended to become self-sufficient in relation to their emotional needs, or gained support from a range of sources, notably from staff at the special schools their children attended. But, what is noticeable in professional literature and research is that when a baby with an impairment grows older, terminology changes, with the terms parents, families, and carers often being used interchangeably. This denotes a change in approach so that having passed on from the 'tragedy' of having a baby with impairments, the concept of the parents as carrying the 'burden' of caring for a disabled child assumes prominence.

A feature of literature on families with a disabled child is the way in which parents and, to a lesser extent, families have been, and are, characterised. Clearly, the way in which parents are characterised in professional literature will impact on the way parents are perceived, and approached, by care professionals, in particular social workers. If they are operating within theoretical frameworks derived from their reading of the professional literature, then it could suggest an explanation for the ambivalence towards social work expressed by a number of the Northern parents. It is not just the characterisations themselves that are a feature but also how authors have striven to place parents in 'frameworks' or 'models'. Professional constructs of parents are a further manifestation of the professionalisation of need, postulated by McNight (1981), and has the potential to engender in professionals the attitude that because they have had professional training, they have a level of understanding denied to those outside the profession. This can result in lay people feeling disempowered, indeed, reference has been made to the Northern parents feeling disempowered by professionals.

This, however, is neither a new or unique phenomenon. Stone and Taylor (1972:40) referred to the exclusion of parents from professional discussions as '*parectomy*', and whilst parents are now included to a much greater extent they can feel equally excluded as a consequence of an unnecessary use of technical and medical language. Many of the Northern parents found this to be particularly so in meetings where they were outnumbered by representatives from different professions, but they also commented that they felt included in school life and decision making by staff at the special schools.

Class has also been shown to be a factor in professional involvement (Humphries & Gordon 1992) with working class families historically forming the primary target for interventions. Whereas, parents able to afford to provide private care for their disabled child were largely left to their own devices. This has established a pattern whereby professionals tend to be drawn from the middle classes and work predominantly with working class people. There is, therefore an inherent risk that professionals will, at worst, endeavour to impose their own values and interpretation of the world onto the people for whom they provide a service, or, at best, allow those values to influence their judgement and assessment of families, *sic* mothers, and situations.

Debates on 'class' as a definition of social divisions aside, data from the study's survey questionnaires did not indicate that the Northern parents were drawn more from one class than another. The registrar general's classifications, based on occupation, do not provide a ready mode of analysis whereby traditional class divisions can readily be highlighted. If anything an analysis of the data would suggest that there were fewer parents from socio economic groups 4 and 5 than from 1,2 and 3. Archer (1998) concluded from research that articulate parents who 'talk tough' get the provision they want for their children. Many of the Northern parents had had to 'talk tough' and, if one accepts that people with a middle class background are generally considered to be more articulate then it would support a conclusion that the

Northern parents were predominantly middle class and had argued for special provision, and got it. The corollary of this would be that less articulate parents had allowed professionals to make the decision and then gone along with it. It could also account for the fact that only one of the Northern parents were a non-white family because if, as Chamba et al (1999) and Shah (1995, 1997) have identified, parents find it difficult to communicate with professionals when English is not the mother tongue, then it is probable that Asian families in particular would face difficulties if they wanted to assert their views. What is unclear is whether or not this resulted in either disabled children being placed at one of the Acorn Societies establishments at the behest of professionals, or that they were placed in other establishments potentially less suitable to meet their child's needs. This may be the case. Many of the Northern parents spoke of having to argue for a specific provision rather than the one proposed by local authority education department representatives. There was, however, no evidence to suggest that education professionals had placed any child in mainstream education, nor was there evidence to suggest that professionals had put inclusion forward as an option.

Professionals in the area of medicine, education and social work feature in the lives of parents caring for a disabled child. However, parents of disabled children could, on occasions, be forgiven for siding with George Bernard Shaw for thinking that 'All professions are a conspiracy against the laity' when they are confronted with the professional attitudes and practices outlined above. In addition parents of disabled children feature as subjects of theories which categorise parents and have the tendency to be accepted as truisms, which have the potential to inhibit the capacity for professionals to work with parents as unique individuals with unique circumstances. Whilst we are all part of history we also occupy personal and parallel histories so, as mentioned above, to see parents of a disabled child as having to fit into an explanation, or set of explanations, of how they feel and, that being so, how they experience the world, is to risk denying them an individual voice. It was seen earlier how the view that parents of disabled children choose special

schools to retain control of their children by maintaining them in a state of 'eternal childhood', led to erroneous assumptions, later shown to be unsustainable. So, parents find themselves pathologised as victims of a tragic event, Anderson and Spain (1977), unthinking socialised objects, Smith (1994), over-protectors sustaining disabled daughters and sons in a state of eternal childhood, John (1988), or martyrs to the cause of caring, Middleton (1992). Conversely, parents are expected to fight for their childrens' rights, Middleton (1992), to be experts on their child's care, Lightfoot et al (1999), and collaborators in developmental programmes, Appleton and Minchom (1991). Such a wide range of perspectives suggests contradictions in the way parents of disabled children are conceptualised in the literature and, therefore, how they may be viewed by professionals, Such complexities are worthy of closer examination. This will, in turn, provide further sustenance for the developing view being put forward that professional perceptions and parent/professional interrelationships influence the way in which parents react to advice, or seek advice, on their choice of a school for their disabled child. Equally, those deeply rooted perceptions of professionals which, it has been argued, have their origins in parents' earliest interactions with medical staff, far from being dissipated, have been consolidated as a consequence of subsequent dealings with professionals in other areas. It has also been shown that mothers are the primary providers of care and assistance so that theorising parenthood often becomes a focus on mothers. The following section will, therefore consider, firstly, models of parents caring for a disabled child as perceived by professionals, those predominantly being, in this instance, social workers. Secondly, models of motherhood, specifically how mothers caring for a disabled child are typified, will be explored. Thirdly, consideration will be given to developments in the concept of the parent/partner/collaborator in the care of disabled children.

Professional models of parents caring for a disabled child

Middleton (1992, 1999), offers a number of theories explaining the relationship between mothers, parents, and disabled children and whilst she provides credible arguments in support of the rights of disabled children, her analysis of parents falls into the trap of providing empirically unsubstantiated explanations which reinforce existing characterisations. The first approach to be considered has proved to be an enduring one. It sees the mother as giving up all and devoting her life to the needs of her disabled child.

> 'Another, not dissimilar, role occupied by a disabled person is that of life-long child. It suits the lifestyle of some families that a child does not grow up, but remains a vessel into which care is poured. A severely disabled child is both non-threatening and permanently grateful. It is all too easy for a parent to slide into the martyr role, which substitutes for all other ambitions and rewards, bringing with it an entire lifestyle.' Middleton (1992:13)

It's somewhat contradictory of Middleton to state that 'severely disabled' children are permanently grateful when, conducting her own research with a group of disabled students, she is able to identify that the group do not, by any means, display permanent gratitude. However, criticisms of Middleton's work aside, this model of motherhood is often linked to religious belief and mothers attributed with carrying out 'Gods will'. There may, of course, be mothers and families who fit this description, but it would be rash for professionals to assume that this is solely the result of having a disabled child. A weakness of such 'modelling' is that because the models themselves are based on generalities and key components, then other aspects of equal relevance can be overlooked. Therefore, the possibility exists, that other factors of equal or greater significance can be overlooked, and all behaviour attributed to the presence of a disabled child, with the dangerous possibility that attempts may be made to change behaviour and attitudes on that basis alone. For example, a parent may not be happy with an education department's decision on where their child should be educated, but they accept the decision. Now, there may a range of reasons why the decision was accepted and the Northern parents demonstrated that there are usually several factors involved in the decision. However, it might be theorised that

socialisation and other sociological explanations provide a more logical reason for this, but is that in itself justification for intervening? Middleton clearly feels that there is a role for the social worker in this area:

> 'Parents assessing the value of the education their child is receiving should be encouraged to ask questions about educational progress, not sucked into discussions solely about how the school is 'coping' with the disability, or how the child is 'managing'. 'How well are you doing in providing my child with an education?' is a more pertinent question than 'How is my child getting on?' **Giving parents the self-esteem to stop apologising for their child and start making demands on educators to educate is a social work task.'** (1992:36) [Emphasis added].

Such an approach hints at professional arrogance in assuming that social workers should, (a) impose their idea of what is right, (b) have a moral authority that is tangible and recognised by the parents and, (c) have the ability and capacity to give parents 'the gift of self esteem'. To encourage such approaches is to encourage social workers to assume that their role is to act as politicisors, and must involve the activation of passive parents.

On the evidence of the accounts given by the Northern parents the view expressed by Middleton does not bear scrutiny. Certainly most parents felt it was their duty to provide care for their disabled child but they did not, on the whole, differentiate between disabled and non-disabled children. There was no evidence to suggest that any of the Northern parents felt the pull of religion borne of guilt, nor did they convey an image of martyrdom. Furthermore, if the Northern parents had had to rely on social workers to raise their self esteem to the point were they would challenge educators then, given the low level of social work involvement, they would have been in difficulties.

Dale (1996) offers an analysis which identifies three main models as having dominated approaches to families with a disabled child.

Firstly, the pathological (sick) model. In this analysis Dale identifies the historical concept, common-place in the late nineteenth century, of disabled people as 'sick' as extending to the family.

> 'Disabled people were treated as the 'patients' requiring medically based treatment. Medical ideas of 'pathology' were extended to families, who were viewed as suffering mainly adverse effects from the disabled person. The birth of a disabled child was seen as a 'crisis' or abnormal state and this concept of 'crisis' was extended to the family.' (1996:101)

An approach not dissimilar to the 'sick' approach is referred to by Dale as the 'sick/coping model'. In this, families with a disabled child are seen as only requiring spasmodic interventions at times of stress. At other times they would be seen as coping with the unusual demands placed upon them by the presence of a disabled child.

> 'Instead of a 'pathological' model, it is more appropriate to think of these families as 'ordinary' families having at times to face specific crises around having a disabled child (Seligman and Darling, 1989). But although many regain ordinary family life, a minority of families remain highly vulnerable and have many difficulties in coping.' (1996:109)

This has all the hallmarks of an abridged 'sick' model inasmuch as there is an acceptance and assumption that certain families will have 'difficulties coping' and, one assumes they will need professional help. How the professional differentiates between the spasmodic short-term requirement for help and the long term need for support is open to question. The danger being that either those who don't need continuous help receive close attention, or those who do need help don't get it. Or, the third way, every family gets the same level of support, regardless of need.

That leads into the last of Dale's models. The definition 'Common Needs Model' gives a clear impression of what is at the heart of this approach.

Namely that all parents and families with a disabled child will have the same needs.

> 'Instead of seeing the child as a pathology, unmet needs for services and material resources *(deficits)* were a major source of stress. This position can be summed up as a *needs deficit model.*' Dale (1996:107)

Dale considers this to be a model which is in considerable use in contemporary service provision and it does have merit. If one considers that many parents, Baldwin (1985), Baldwin and Carlisle (1994), Beresford, (1994a, 1994b, 1997), Glendinning (1983), have had to cope with little or no support from statutory bodies then even a common 'off the shelf' package would supply much more than they have been accustomed to. One can also see the attraction this approach could have for service providers and budget setters. If one has a family with a child with a particular range of impairments then it should be straightforward to cost out a standard package of care and then, having identified all the families in the administrative area eligible for the 'package', cost out the package and supply it on a supposed 'needs led' basis. However, whilst it has attractive qualities there is the inherent danger in such approaches. Inasmuch as if there is the assumption that all families will have the same, or similar needs, then there is the potential for families caring for a disabled child to be homogenised, thereby de-personalising those families. As a consequence unless there is also scope for flexibility within the 'common needs' approach, then unmet need could go unacknowledged with individual requirements remaining unidentified.

The range and level of needs identified by the Northern parents had some core elements, information, emotional support, and safe respite care, being three areas of need frequently voiced. However, there were also issues specific to individual families, and individual family members, as well as the common elements highlighted above, which pointed to support services needing to have the capacity to be flexible, and demonstrate a degree of variability. Indeed, what can be concluded from the Northern parents is that

whilst 'modelling' parents might enable professionals to approach work with families caring for a disabled child with a baseline evolved from a theoretical framework, professionals would do well to approach parents and families in an open and flexible frame of mind.

Thus far the section has predominantly featured models which focus on families as a whole unit. However, the Northern parents' study evidenced the reality, that it is mothers who have the key role in the care of disabled children. However, as pointed out above, focusing on parents as a unit denies the reality of the situation. That reality being that it is mothers who provide the bulk of care, support and assistance. Consequently, to further the argument being made that special schools provide a degree of support missing from other sources, it is important to contextualise the Northern mothers' experiences of working with professionals so that those experiences can be compared with those of parents caring for a disabled child in general. This will offer further indications that the relationship between, in this instance mothers, and special schools, has positive benefits which influence the choice of a special school. The section will, therefore, now move on to look at some of the complexities lying beneath the concept of motherhood.

Mother's role, motherhood, and mothers caring

This section will consider a variety of roles performed by mothers, and those they are expected to perform, as a consequence of being a mother, and specifically, one caring for a disabled child. There will be a consideration of how mothers are idealised, how they see their roles, and how the weight of social expectation impacts on the ability of mothers to have autonomy.

The early part of the section focused largely on the collectives of families, and parents. However, there are professional attitudes which confer a special status on mothers, notably, the 'ideal mother' Strong (1979), and the 'good

mother' Anderson (1976). The imputation is that mothers are seen as good and ideal for no other reason than that they are mothers.

Strong conducted research in a clinical setting with the objective of exploring the relationships between medical clinicians and parents. Although the research was conducted over twenty years ago it is as relevant today as it was then. Strong found that:

> 'Every mother, just because she was a mother, was an ideal mother, someone who naturally wanted and loved her children and cared for them with a wholly natural competence. Likewise, every mother made an ideal representative. Children might not know how to fend for themselves in medical consultations; but there was little to fear, for their mothers were honest, intelligent, reliable and impartial; or so the story ran.' (1979:40)

The implication in Strong's closing remark is that this may not be the case and, therefore, assumptions cannot be made, on the basis of biological motherhood alone, that all mothers, if any, will possess the qualities assigned to them by medical professionals.

A further element of this presumption is seen by Anderson as having consequences for the way mothers may present themselves in relation to the identity ascribed by society to the mother :

> 'Professionals often appear to be unaware of the stressfulness of this issue for mothers. They are not entirely to blame, since on their part mothers often try to conceal the strength of their feeling, the better to play the role of the 'good' mother which society demands of them ....' (1976:112)

So, not only is there a probability that assumptions will be made about a mother's ability to provide nurturing, and to know of and relate her child's views and wishes; but that a mother will also conceal her real feelings because of a socially constructed role she feels she must conform to. Graham's (1993) research identified that whilst mothers do take on the responsibility for their children, it is not in a spirit of moral rectitude.

> 'Taking responsibility for the needs and care of young children involves many mothers in a day-long and life-long struggle to shield them against oppression and discrimination. Mothers caring for disabled children try to provide a supportive environment in which their children can build strong and resilient identities.' (1993:77)

Graham presents the role of the mother as a struggle borne out of the desire to do the best for their child and not because of expectations of either professionals or society.

It was evident from the accounts of mothers in the Northern parents that not only had they assumed, almost *a priori* , that it would be their lives that would change to fulfil the care needs of their newly born baby with an impairment, but also that they would continue to be the primary carer and advocate for their disabled child. This was also the case for parents whose child had had their impairment identified later.

The role expectation identified above by Graham (1993), and notions of the 'good mother' proposed by Strong (1979), fit with other analyses of women and motherhood, which offer further explanations for the experiences of the Northern mothers. Chodorow (1978) illustrated how the role of women as primary care providers had been reproduced over generations. Phoenix and Woolett (1991) talk of motherhood as being seen as the supreme physical and emotional achievement a women can achieve, whilst the task of mothering is socially devalued. Silva (1996) adopts a similar theme when she refers to mothers as having been seen to have the power to shape and influence, whilst, since industrialisation, motherhood has undergone a process of degradation since the *'historical golden age'* (:10). On this basis it would appear that the social construction of motherhood has undergone change and that there is an element of ambivalence associated with, on the one hand, reproduction and the act of giving birth, which has an almost mythical status in contemporary society; and on the other hand, the process of mothering, which is given a low status. Ambivalence is also a concept

embraced by Parker (1997) who explores the notion that mothers function in a state of maternal ambivalence by concurrently both loving and hating their child. Loving the child as the person he or she is, yet hating him or her for the role, status, and function the mother is forced into as a consequence of being 'a mother'.

However, there have been criticisms that this emphasis on motherhood results in fathers being marginalised with little regard given to their feelings and wishes to care for their disabled child. Hornby has argued that:

> 'this ignores any role the father might play. Much of the research to date has focused on the effects on mothers or siblings of disabled children and little attention has been paid to fathers.' (1992:363)

However, whilst there is a case to be made for considering fathers in relation to the provision of care for disabled children, the literature unequivocally concludes, Barnes et al (1999:99), Glendinning (1983), that the stark reality is that it is mothers who not only perform the vast bulk of personal care and assistance, but significantly, they are also expected to do so. As Abbott and Sapsford found:

> 'The work of community care, despite genuine assistance received in some cases from the family, the community and the state, tends to fall over-whelmingly on the mother, Similarly, despite the effects of handicap on the whole nuclear family which have been documented above, it is the mother's life and life opportunities which are most disrupted by having a mentally handicapped child.' (1992:53)

All these elements could clearly be seen in the responses of the Northern parents. Mothers expressed their frustration at having had to alter their lives to provide care, yet stating that they would have it no other way. It was also evident in the way in which they had an ambivalent approach to continuing to provide care in to adulthood. There was a clear expression that although they felt it was an obligation expected of them by society, they too felt that it was what they should do. However, it was also evident that they hoped for

some alternative which would enable them to fulfil what they saw as their duty to a child, without necessarily supplying the day-to-day care. It could be surmised that the model established by the special school would be one that mothers could see as being developed. That is, a collaborative arrangement which recognised the role of the mother, and parents, as being important. This point will be returned to below.

Professional perspectives on parenthood, and motherhood, in relation to disabled children have concentrated on the perceived psychological and emotional state of parents. One aspect, raised by Middleton (1992, 1999), and earlier by John (1988), is the view that parents prevent their disabled child from attaining adulthood by keeping them as eternal children by ensuring that they remain dependent on, supposedly, mothers. This mainly focuses on mothers who are seen as the empty vessels needing to be filled by the dependence of their disabled child. This is especially problematic when a disabled child nears that stage in their lives, termed the 'transition to adulthood', when parents are seen to be at their most obstructive. However, it is not necessarily viewed as being the fault of parents, but rather that they need support, Morris (1999a, 1999b), to help them through this process. Interestingly, the transition for disabled young people is seen as being far more problematic than it is for non disabled children who, implicitly, are assumed to make the transition unaided. There is, however, an acknowledgement that there are similarities between disabled daughters and sons living away from home and non disabled offspring who may return home or seek support from parents, Morris, (1999a). Nevertheless, non disabled offspring returning home do so for many different reasons; broken relationships, financial hardship, being two examples. Rarely would non disabled offspring return home because their package of care had broken down, or a local authority had failed to meet it's obligations to provide a required level of care. The following account is an illustration of the situation parents of a disabled young adult living in independent accommodation can face:

> 'A disabled person's parents called, frantic that social services were about to place their son in an institution. He had been receiving LA services for a number of years. These had broken down from time to time, particularly over Christmas and he'd also had cause to complain about one of the workers.' BCODP (June, 2000)

Nor would parents of non disabled offspring living away from home be likely to worry that their daughter, or son, was at risk of abuse from support staff, or were vulnerable to abuse from acquaintances or strangers. Not surprising then that many of the mothers in the Northern parents expressed concern about how their son's and daughter's would manage if they moved away from the family home.

Moving away from home is often seen as the way disabled young people will achieve independence, the clear implication being that living in the family home will prevent them achieving independence. However, research by Bignall and Butt (2000) found that young black disabled people did not necessarily see moving away from home as leading to independence. Their view was that it was being in control and making their own decisions that determined independence, not where one lived. Parents either appeared to promote this position for their children, or make it problematic, because of over protective attitudes, and the creation of a feeling on the part of the disabled young adult that they would not be able to get the level of care their parents' provided if they left home. Bignell and Butt's findings illustrate that parents cannot be stereotyped as obstructionist, and challenge the dominant professional perception that independent living means living outside the family home in some form of self-contained residence.

The above illustrates that the position of parents in relation to achieving independence and rights for their disabled child can be seen to be ambiguous. On the one hand they are urged in the literature to argue their child's case, Middleton, (1999). They act as experts advising teachers in mainstream schools on the correct care for their child, Lightfoot, Wright and

Sloper (1999). And they mediate between their disabled child and the world, Read (2000). Indeed, the Northern parents saw their role as advocates as being intrinsic to their role as parents, and one they would perform for all their children. However, the issues for disabled children are clearly distinct from those of non disabled children as Atkinson (1999) highlights. Atkinson concludes from her review of literature and advocacy projects that, while there is an active and growing range of advocacy services available to people who need them, there are significant gaps. Those gaps indicate that parents of disabled children are wise to see themselves as having to perform an advocacy role for their disabled child because the gaps in advocacy service were in the areas of:

> - Children and young people using public services of any kind.
>
> - Children and young people at risk of family breakdown, school exclusion, poverty, neglect or abuse.
>
> - Disabled children, especially those who are living away from home much of the time, or 'looked after' by the local authority.
>
> - Black and Asian children and young people, and children from other ethnic minority groups who are disabled and/or being looked after away from home. Atkinson (1999:29)

Read (2000), identifies that mothers also perform a somewhat more complex role than advocacy for their disabled child. Read highlights the way in which mothers act as mediators by translating meanings into a form which both conveys the essential truth, whilst protecting their disabled child from the damage a literal translation would inflict. In the case of the Northern parents this role of mediator was extended to mediating between siblings who were perplexed at the way their disabled sister or brother was treated when outside the home. As Debbie said to her daughter who questioned her about the way people in the street were looking at her brother "*I don't know. Maybe it's because he's so good looking*".

Parents, then, find themselves chastised in professional literature if they do not press for their child's entitlement, although this results in them being seen as troublemakers, Philp and Duckworth (1982), by service providers. But yet when they act in what they see as their child's best interests, as they approach adulthood, they are pilloried for being 'over protective' and for being unable to 'let go'. Parenting is rarely presented as easy, whatever abilities children may have, but parenting a disabled child carries with it additional tiers of responsibility requiring additional skills and qualities. Not those of the hero, or the martyr, but those highlighted in the previous chapter, realism, practical common-sense, and flexibility. It is not unsurprising, therefore, if a special school is chosen where parents feel valued by staff, rather than feeling judged. However, despite the ambiguity of the professional literature, professionals have created roles for parents of disabled children, and these will feature in the next passage.

Parents as partners

The power and capacity of mothers to 'shape' identified by Silva (1996), has been acknowledged by care professionals and adapted to comply with the needs of professionals. So it can be seen how professional approaches to work with parents of a disabled child can now be characterised, by the concept embodied in the term 'working in partnership'.

Developments in the way professional services are provided and theoretical approaches to work with disabled people, such as normalisation, an approach which will be developed in the next chapter, have, as one consequence, meant that professionals working with disabled people have developed strategies to involve parents. Parents are seen to be in a position to augment the sessional and sometimes intermittent interventions of workers. How much workers value this involvement is questionable, or whether it is viewed as necessary but not something that would be done from choice, remains a point of conjecture. However, the roles performed by parents have evolved

over the last two decades or so and can be viewed as distinct approaches. Parents do not always see their involvement as being a 'para-professional' and can see professional expectations of what they can achieve as unrealistic. Some of the Northern parents commented on how teachers did not fully appreciate the demands that routine caring placed upon parents, and expected them to undertake activities and tasks with their disabled child which could not be achieved.

Read (1985), sub-divides this style of professional involvement into two, that of parents as 'change agents' and parents as 'partners'. The difference being that in the case of the former the parents are expected to carry out therapeutic or behavioural programmes, designed by professionals, under the guidance and control of professionals. In the case of the latter there is a concept of sharing wherein the professional 'shares' their expertise and skill with the parents who will then work with their child, thereby creating a collective and shared strategy.

The potential of parents does not go unnoticed by Anderson and Spain:

> 'The parents' attitudes and activities will be the main influences on a child's progress and consequently nothing that professional people themselves can offer to the child will have as great an impact on him as the counselling that they give to the parents. First and foremost parents must be helped to recognise their own value as therapists or educators in the broadest sense.' (1977:89)

Read points to the development of parents as 'agents of change', which arose in the mid 1970s as a consequence of the growth in clinical and educational psychology. Psychologists, she argues, realised that they did not have the time necessary to effect the required changes in child behaviours, bearing in mind that at that time the dominant psychological approaches were behaviourist, the solution therefore was to use parents. Referring to a research project conducted by the Hester Adrien Research Centre at Manchester University, she comments:

> 'They justify the involvement of parents on the grounds that parents are a primary influence on children's development, that the numbers of children requiring help outnumbers the professionals available, and that parents of mentally handicapped children are anxious to help their children's development.' (1985:20)

So, parents were seen to have qualities, previously unacknowledged by professionals, which were now deemed to be of use. Which came first is hard to discern; a recognition of parents' qualities, or a professional need for auxiliary help in implementing behavioural programmes. Be that as it may, this approach was to merge into one more akin to partnership, although the real nature of parent/professional partnership might be questioned, given the power still retained by professionals in relation to access to resources. That is to say it is difficult to know, in the absences of research, if parents felt obliged to comply with professional aspirations, or lose services. Equally, parents having been accustomed to having to challenge professionals may feel flattered, or just relieved, not to be in a state of confrontation, so that they go along with professional requests to maintain a good relationship. This, however, remains at the level of conjecture, although there was a discreet implication in the way some of the Northern parents referred to professionals, which pointed to such conjecture as having some substance.

The concept of parents as partners is not restricted to professional workers alone. Indeed, it has featured in government reports. It was specified in the Warnock Report 1978, which formed the basis of the Education Act 1981 and it also featured in the Children Act 1989. Partnership and the involvement of parents in planning care packages and other plans relating to their children became, through the development of social policy, embedded in contemporary legislation. Consequently, contemporary legislation which directly affects disabled children, the Education Act 1993 (consolidated into the 1996 Education Act) and the 1994 Code of Practice, and the Children Act 1989, which 'requires' professionals to work in partnership. However, how a

partnership is defined will depend on who is defining it, and what criteria are being applied.

Dale defines partnership thus:

> 'The parent-professional relationship is a formal one, with each partner taking up a specified social role in relation to the other. The roles of 'parent' and 'professional' impose certain rights and duties on the incumbents of each position to do with how that role position is constructed in society. Each position carries a set of associated norms, obligations and expected behaviours, and, as a result, each partner has expectations of how they or the other should behave together.' (1996:3)

This description establishes that there are differences in the partnership relationship between 'parent' and 'professional' and whilst it may seem simplistic to say so, of course there are. On the one hand there is an 'expert' who has usually undergone professional training and who is paid to do a job. On the other hand there is the parent, 'inexpert' due to an absence of training or experience (at least in the early life of a disabled child) who spends all their time, because, as has been established in the research and above, it is invariably the mother, caring for their child; for no financial gain. It is plain that the quality of the partnership will owe far more to the skills and abilities of the professional than to the enthusiasm of the parent. Whilst mothers are recognised as having skills, and even as experts, Lightfoot, Wright and Sloper (1999), on their own child, this is often restricted to a recognition that they best understand their child's 'care' needs and can offer advice in that area only. Given that the Northern parents had little contact with social workers, other than to arrange respite care or request aids and adaptations, there was little evidence of any of the Northern parents working in partnership with social workers implementing behaviour modification, or other forms of programmes. However, parents of children attending Ash school (the establishment for children with autism) worked with teachers and speech therapists, but this was not defined as implementing a programme but rather continuing to interact with their child using the approaches developed by staff.

Parents did not allude to this in a way that suggested partnership. Their feelings could best be defined as operating within a 'team' approach, in which they saw themselves as having a key role to play in the strategy developed for their child. Indeed, it was apparent that parents both valued the relationship with school staff, and felt that they were also valued by the staff.

But, whilst mothers play the dominant role in supporting programmes aimed at developing their disabled child's abilities, Anderson and Spain make a case for involving fathers more:

> 'The initiative should not be left entirely with the mother since sometimes she does not encourage her husband to attend clinics in order to spare him distress. It should be made clear to the father, from the beginning, that his attendance at the clinic or the school is seen to be important. Undoubtedly the support and help that a fully participating father can give to the family far exceeds anything that can be offered by professional people. (1977:91)

Anderson appears to be implying that the father will act as some sort of 'quasi-professional' by offering support - not really full participation. This would tend to indicate that the assumption here is that the mother will be the primary carer with the father supporting, when appropriate. The ambivalent relationship between professionals and fathers was identified by Hornby in his review of literature on fathers with a disabled child:

> 'It is reported in the literature that fathers tend to become cut off from sources of social support generally and specifically that they often resent the attitudes and lack of help from neighbours and workmates (Cummings, 1976; Lamb, 1983). However, the negative reaction to professionals is a disturbing finding which is seldom reported in the literature and therefore requires careful consideration. What is reported in the literature is that fathers typically have much less contact, than their wives, with the professionals concerned with their disabled children (McConachie, 1986; Philp and Duckworth, 1982). Therefore, they do not have the same opportunities as their wives to develop productive relationships with the people working with their children. Also, much of the information they get from

> professionals comes to them second hand via their wives, which is a communication process that can lead to misunderstandings.' (1992:372)

Whilst this correlates with the experience of the Northern parents, whereby mothers did have much more contact with professionals, and whilst the positive gains to be made from fathers being more closely involved are well stated, the possibility of that happening are slender. Whilst the sexual division of labour within the households of the Northern parents is evident, a sociological analysis does not substitute for earnings. So, if mothers are limited in their capacity to work it inevitably falls on fathers to earn as much as they can to support the family. In addition, if fathers go out to work, and professionals work during the day time, then professionals are more likely to have sustained contact with mothers. These issues will form the themes of the discussion which follows in the next section, which will be a consideration of the social circumstances of families with a disabled child.

THE CIRCUMSTANCES OF FAMILIES WITH A DISABLED CHILD

The study, and the literature discussed thus far, has established that the birth of a baby with an impairment is viewed generally as a *'disaster'* Barnes et al (1999), and that care is predominantly provided by mothers. Furthermore, mothers act as advocates for their disabled child and mediate, Read (2000), between them and the extrinsic world. The sexual division of labour within households where care is being provided for a disabled child has been shown to be clearly etched so that, in most cases, when partnerships are developed by professionals working with the families of disabled children, they are with mothers. Professional attitudes towards the birth, or presence, of a disabled child have been shown to be significant in the way professionals view working with parents who are often, typically, stereotyped as 'heroic'. But, it has been highlighted that the lives of parents caring for a disabled child are complex,

with the previous chapter pointing to the role played by special schools in the lives of parents caring for a disabled child, as forming a key component in parents' coping strategies. So, placing the circumstances of the Northern parents within a wider social context will provide further illustrations of the interface between special schools and parents caring for a disabled child which sheds further light on the choice of a special school. It should be noted, however, that whilst it is acknowledged that the financial cost of bringing up a disabled child is three times that of bringing up a non-disabled child, Dobson and Middleton (1998), the study did not set out to establish the financial circumstances of the Northern parents. Nonetheless, to completely ignore the literature on finance and families with a disabled child would be an avoidance of a significant aspect in their lives.

The accounts of the Northern parents, and the literature, have clearly identified that, when it comes to caring for a disabled child living at home 'family' is a euphemism for 'mother'. Consequently, because the study identified that mothers provide the majority of care, support and assistance for disabled children living at home, and because this was echoed in the literature, an emphasis on the social circumstances of mothers is both inevitable and necessary.

A note here about terminology. It will have been noted that the term 'carer' appears on a number of occasions. That is because a number of researchers define parents as carers, thereby identifying the role performed by parents of a disabled child as being different to that of parents who do not have a disabled child. This is perhaps reasonable when children become adolescents and parents are carrying out tasks for their children which, if they did not have an impairment, they would be doing for themselves. However, tasks performed for small children do not differ to such an extent between disabled and non-disabled children. There is merit in the use of the term 'carer' in relation to young adults because it illustrates the changing nature of the parental role and, to a small degree, weakens the concept of eternal

childhood. Whilst the parent is, self-evidently, still the parent, the different nature of their relationship with their daughter or son is, arguably, more explicit if defined in relation to personal care and assistance.

Research, Abbot and Sapsford (1992), Audit Commission (1994), Baldwin and Carlisle (1994), Baldwin and Glendinning (1982), Beresford (1994a, 1994b, 1995, 1999), Chamba et al (1999), Dobson and Middleton (1998), Glendinning (1983), Hirst (1985, 1992), Hirst and Baldwin (1994), Kagan et al (1998), Meltzer et al (1989), Philp and Duckworth (1982), Read (2000), and SSI (1994), on, and with, families with a disabled child, has consistently concluded that the circumstances and experiences of families with a disabled child are both quantitatively and qualitatively different to those of families who do not have a disabled child. This manifests itself in a range of situations. Where differences are identified there is a tendency for some of those differences to be conceptualised as 'costs'. For example:

> 'The adverse effects, or costs, on carers of looking after a severely disabled person are many and varied. Baldwin & Glendinning (1982) draw a broad distinction between opportunity costs (e.g. restricted social life), psychological costs (e.g. raised stress levels), and financial costs (e.g. loss of earnings, extra spending). They also emphasise, following Wilkin (1979), that identification of such costs does not imply that severe disablement inevitably has abnormal and pathological effects on families.'
>
> Hirst (1985:292/293)

A potential consequence of using methods of data collection which focus on 'deficits' is that experience of having a disabled child is further defined as being negative. Therefore, there is limited scope for the positive experiences and feelings to be expressed and published. However, Beresford offers an alternative approach:

> 'The basic premise of this alternative model is that it is essential, given that carers have to deal with the increased stresses, and what factors help them to cope. This approach redefines the issue of caring in a number of ways. First, it does not pathologise caring, that is, it does not assume that

> caring invariably has an adverse effect on the carer. Secondly, the fact that many carers do adapt and cope with their situation is emphasised. Thirdly, carers are redefined as active agents as opposed to passive recipients of an onslaught of carer-related stress. What carers actually do to manage problems and difficulties becomes the focus of attention.' (1994b:2)

Ontological issues were touched upon in Chapter 1 and it was concluded that approaches such as those exemplified by the one advocated by Beresford, allow for the generation of new knowledge and new perspectives on established social institutions. Whilst caution needs to be exercised so that, by focusing on the ways in which carers 'manage problems and difficulties', structural factors which create many of the situations which become 'problems and difficulties' are not allowed to be submerged under personal experience. However, this can be avoided if structural circumstances are defined and integrated with the experiences of individual parents. The following discussion will, therefore, identify structural factors and interface them with parents' views

The 'cost' of caring

Baldwin & Glendinning, (1982), grouped costs resulting from caring for a severely disabled person into three categories, viz.:

- Opportunity costs (e.g. restricted social life).
- Psychological costs (e.g. raised stress levels).
- Financial costs (e.g. loss of earnings, extra spending)..

The term 'costs' can have a number of meanings, but costs are usually seen as something incurred as a result of an action. In legal circles costs are what one pays for bringing a legal action against a second party. In manufacturing costs are incurred as a consequence of producing a commodity. Generally

speaking then, costs are a necessary by-product of an action and can therefore be seen as having been incurred knowingly, albeit as a routine social practice. To see caring for a disabled child in these terms is to see caring as a deficit incurred as a consequence of the child's impairment. However, this ignores the 'action' element which is a feature of the normal usage of the term, so costs are seen as deficits which, as there is no ostensible end-product, must be borne without recompense. But, if costs are incurred which cannot be recompensed then, following the above line of argument, there must be a reason. That translates into the negative image of caring for a disabled child, that of it being a burden, because if that child is the reason costs cannot be recovered, as well as being the cause of the costs, then surely it is a burden. However, the reasons for the inability to recover costs will be seen as largely structural and perpetuated because of the failure of services to provide support for parents.

It is acknowledged that divisions such as those proposed by Baldwin and Glendinning (1982) can obscure the complexity of the consequences of caring for a disabled child. So, where there is overlap or consequential factors these will be discussed. Notwithstanding, the categories will be taken sequentially, with, firstly: opportunity costs.

Opportunity costs

A number of consequences resulting from having a disabled child are difficult to quantify. These are largely seen to be opportunities which cannot be taken because of the demands of caring for a disabled child. Philp and Duckworth's (1982) review of research found that parents encountered 'problems' across a range of social activities and had difficulty participating in leisure activities because of cost. This was also exacerbated by the degree of a child's disability;

'Families containing intellectually or multiply impaired children were especially restricted...' (1982:21)

Holidays were also found to be problematic and that:

'Most of them [parents of a disabled child] did not need to make special arrangements. At the same time their holiday experiences led many parents to think in terms of accepting special holidays for the child in the future.; (Ibid)

Hirst found that women's employment opportunities were restricted when they were caring for a disabled daughter or son:

'Comparisons between this sample [Hirst's research sample] and the GHS [General Household Survey] showed that the employment patterns of women with a young disabled adult were very different from those of women in the general population. Mothers of disabled young adults were much less likely to be in paid employment. When they did go out to work, they were much less likely to be in full-time employment.' (1985:302)

Baldwin and Gerard highlighted the range of opportunity costs:

'For the principal carer - almost invariably the child's mother - the opportunities for leisure time - for doing things they would otherwise do such as reading, watching television, going out socially, even sleeping. Interviews with mothers, (see Glendinning 1983) demonstrated the frustration of being unable, for example, to attend evening classes, study for A levels or train for a new career' (1990:134)

Baldwin and Carlisle's 1994 review of literature also concluded that:

'Parents are likely to find there own social lives restricted - because of fatigue, difficulty in finding baby sitters or financial stress.'

and

'Taking family holidays can be equally problematic because of difficulties in access, managing the child's treatment, behaviour problems and so on.' (1994:21)

Baldwin and Carlisle point to the difficulty in getting a 'baby-sitter' as one reason for parents low participation in social and leisure activities. It is not just baby-sitting but also the need for someone to sit-in with older disabled children and young adults. Mothers in particular have found it difficult to access forms of support normally associated with child rearing, like neighbours, friends, and family members which can lead to isolation:

> 'Whereas other mothers may look to the support of neighbours and friends to help them through, women with disabled children can find themselves isolated within their local communities.' Graham (1993:91)

Beresford also identified fear of leaving a disabled child as a further factor:

> 'Parents may be afraid to leave their child, or want to defend themselves from the reactions of others (Carver & Carver 1972, Harrison, 1972).' (1994a:181)

It is apparent that parents, and particularly mothers, encounter difficulties in pursuing activities that parents of non-disabled children would not face, or at least to anything like the same extent. This is because caring for a disabled child requires more time, and severely restricts scope for flexibility because of the need to be 'on-call' to respond immediately to demands resulting from unpredicted crises in their disabled child's regime, or sudden illness. Tiredness because of interrupted sleep and the physical element that is frequently inherent in caring, also reduce the motivation to pursue outside activities which, when added to problems in finding someone trusted by the parents to sit-in whilst they are out, can result in social isolation.

The above accords with the study with the Northern parents expressing that they had difficulty with all the aspects of social life identified in the above research. They too found problems with holiday arrangements, going to the cinema and similar family outings. Mothers expressed feeling isolated and separated from their peers. A further feature in the Northern parents' accounts was the limited number of people they could call on to 'sit' with their daughter or son, and with whom they felt their child would be safe. Or, to be

precise, who they, the parents, felt safe with. Such support tended to be limited to immediate family, such as, their own parents, elder children, and their own siblings. In the circumstances it is unsurprising that parents valued the sense of safety enjoyed by choosing a special school for their disabled child.

Other factors also combine with, and contribute to, those mentioned above to exacerbate the situation for parents caring for a disabled child. Broadly speaking these are the other two 'costs' mentioned above. One of those was health, and that will be the focus of the next section.

Psychological and health costs

Although the introduction to this section stated that Baldwin and Glendenning's broad categories would be used, one of which was 'psychological costs' , it seems inappropriate to separate 'health costs' from 'psychological costs'. It could be argued that psychological and emotional states are not health, or that health would be better placed under opportunity costs, but a division between physical and mental health is fallacious and could lead to further stereotyping of mothers as 'victims' of mental illness, particularly depression. The section will, therefore, consider health costs seen as being incurred as a consequence of caring for a disabled child, generically.

Sufficient research exists, Chetwynd (1985), Eiser (1990), Glendinning (1983), Meltzer et al (1989), Much (1997), Parker (1990), Quine and Pahl (1985, 1991), to support the view that parents, particularly mothers, with a disabled child experience high levels of ill health and emotional stress. The Northern parents commented on how caring for a disabled child created an emotional strain on the family. Although stress levels were high they did not, in themselves, create a continuous problem. Rather, the Northern parents

felt, there were times when the cumulative effect of stress became difficult to cope with. This view concurred with Philp and Duckworth who concluded that:

> 'Taking all studies together, there is reasonably firm evidence that the parents of children with disablement are more likely than parents of children without disablement to suffer from stress, anxiety and depression.'
>
> (1982:36)

Meltzer et al found that:

> 'Thirty-seven per cent of mothers thought that having a disabled child did affect their health.'
>
> and:
>
> 'The most common problem mentioned by three-quarters of mothers in relation to their own and their spouses health was anxiety and depression. Other major health problems in order of the frequency with which they were commented on were: tiredness and exhaustion, physical ailments like weight loss and feeling bad tempered and irritable.' (1989:68)

Hirst concluded that the nature of young adult's impairment also affected the incidence of stress:

> 'The relationship between mothers' GHQ [General Health Questionnaire] scores and young adults' impairment and disabilities were therefore examined. Mean GHQ scores varied significantly according to young adults' impairment: mothers of physically impaired young people had lower scores on average than mothers of the mentally and multiply impaired .... This suggests that higher levels of psychiatric disturbance were associated with caring for intellectually impaired young adults.' (1985:296)

With evidence demonstrating that having a disabled child at home did create heightened levels of anxiety and stress and also indicating poorer levels of general health; research has also considered what specific factors were perceived to be the cause of stress, and subsequently, what coping strategies parents adopted.

Baldwin and Gerard identified a wide range of causal factors:

> 'Coping for long periods with what Bayley (1973) terms 'the daily grind' of care, not only lifting, toileting, and feeding, but also the increased laundry and other house work created by incontinence, sickness, and behaviour disturbance, is hard and debilitating work, particularly when sleep is regularly disturbed. Many parents report effects on their own health such as backache and high blood pressure, while the necessity of providing such continuous high levels of care and supervision inevitably restricts the lives of parents and other children in a large number of ways.' (1990:134)

A number of the Northern parents also referred to chronic health issues. An example of this were Janet and David. Janet had acquired a chronic back condition as a consequence of lifting Simon, so David now had to lift Simon, but he too was beginning to experience problems with his back. Consequently they were both experiencing anxiety about how Simon's needs could continue to be met by themselves.

Baldwin and Carlisle reinforce this point in their review of the literature:

> 'The emotional stresses reported in the literature include many centring on the child and her condition - anxieties about illness, death, what will happen when she grows up. They centre often on milestones not reached and on transitional phases - starting school, adolescence or school leaving age. They also extend to worries about effects on other children and on partners. The hard practical work and the isolation resulting from restrictions on social lives and from restrictions on employment is clearly a potential source of emotional strain, particularly, perhaps, for single parents.' (1994:22)

The consequence of providing care, the physical effort and emotional demands, create a greater likelihood of physical illness and the potential for mental disorder. However, there are two notes of caution to be exercised when considering this information. Firstly, the assumption should not be made that because a mother is caring for a disabled child she will *de facto* be

depressed or ill. Secondly, how might the fact that all mothers, and parents, looking after a disabled child at home do not experience higher levels of physical illness and emotional disturbance, be explained? Beresford et al (1999), endeavoured to establish some explanation for this when they looked at what disabled children and their families considered worked for them in relation to services and support. Much of what Beresford et al found concurred with the views of the Northern parents, Interestingly though, many of the services that worked for the families in Beresford et al's study, such as the provision of information and links with other families, were accessed by most of the Northern parents as a consequence of their child's attendance at a special school, rather than resulting from statutory intervention or formal non-statutory groups.

The literature reviews mentioned above, Baldwin and Carlisle (1994), Philp and Duckworth (1982), whilst identifying causes of stress also highlight the need to focus on how parents themselves perceive caring for a disabled child. They emphasise the need to move away from the pathologising which epitomised earlier approaches in both research and professional practice. These approaches were discussed above, and the negative elements attached to psychoanalytically dominated interventions, which located problems within the mother, parents, or families, were considered to be counter-productive. However, there was sufficient evidence, Middleton (1992), Quinn (1998), to suggest that pathologising mothers, and parents, is still a feature of some publications aimed at professionals in the fields of health and social care.

When support from family members is available, and support networks in place, then it has been found that parents experience less stress, Beresford et al (1999), Much (1997). A number of the Northern parents identified their sources of support. Some had family but, as mentioned above, they used them sparingly. Others had access to periodic respite care whilst others had friends. However, a substantial number of the Northern parents had none of

the traditional methods of support and found their support from other sources. A major source of support for most of the Northern parents came from the special schools. This did not just entail support from teaching and care staff but from the networks which developed amongst parents themselves. The clear conclusion is that support is essential and offers further evidence for why parents choose to both place and keep their disabled child at a special school. This point will be returned to but, in relation to support, the literature is clear: where there are networks of support from both formal and informal sources, stress levels are lower. Also, when parents are not in conflict with statutory agencies over the provision of services then stress is lower. Beresford offers an example of this in relation to educational provision:

> 'Dissatisfaction with schooling can leave a parent feeling at odds with service providers and isolated in his or her fight to provide the best for the child. In contrast, where parents were experiencing a high degree of involvement and interest from professionals, parents felt enormously supported.' (1994b:112)

As well as support from statutory organisations and informal networks Beresford's (1994b) research also identified a variety of coping strategies, similar to those expressed by the Northern parents, employed by parents which she terms *'approaches to life'.* Approaches were generally pragmatic, philosophical attitudes such as 'taking one day at a time'. Indeed, Beresford's findings clearly demonstrated that parents were unwilling to consider the future of their child, because of uncertainties over what that might be which, in turn, led to feelings of helplessness and having no control over future events. Therefore, by focusing on the practicalities of getting through each day the stress of future uncertainty was alleviated. A consequence of this approach, however, is that at transition points, such as starting or changing school, stress levels heighten because parents are compelled, by virtue of having to make a choice, and because of the intimidating nature of the educational and transitional review process, to consider the future.

Viewing the future was also identified by the Northern parents as being an area which they largely chose to ignore. The reason given was usually that they feared the unknown, inasmuch as they had no idea of what services would be available or how they would be able to continue to cope. This was complicated by the factors highlighted above. Namely the obligation, borne of concepts and ideologies of motherhood, that mothers will continue to provide care for their child. Indeed it has been argued, for example Lister (2000), that social policy is 'genderised' so that social expectations are that women will provide the care that is needed. Lewis (2000:41), has pointed to the devaluation of womens' caring role and argues that *'no modern welfare state has found a way of valuing care given by women'.* But, mothers concerns went beyond concern for their daughter or son's future or, indeed, their own. Other members of the family were seen as bearing some of the cost generated as a result of caring for a disabled sister or brother, and these will be discussed in the following section.

The impact of caring for a disabled child on siblings

Mothers, in particular, felt that caring for a disabled child had an impact on the sisters and brothers of the disabled child. Mothers considered that siblings suffered because of the amount of time caring for a disabled child consumed, and the consequent reduction in time this meant they could spend with their non disabled children. This was felt to impact on the time parents could spend helping their other children with schoolwork or spending time talking and playing. There were also consequences for the scope of leisure activities they could undertake collectively, so that it was felt that activities were constrained by needing to ensure venues were suitable for the disabled sibling. This can be defined as an opportunity cost but has also been identified as having other consequences.

McConachie (1983) found that children with a disabled sibling felt that they lost out on activities as a result of the needs of their disabled brother or sister. In addition they experienced a range of emotions, including anger, although they took part in providing care and also had more positive attitudes towards disabled people. McConachie highlighted that research had largely ignored the views of siblings whereas her research included their views. However, although this had been the pattern, research conducted by Atkinson and Crawford (1995) was concerned solely with the views of siblings. They found similar emotional responses to those of McConachie (1983), with brothers and sisters of disabled children expressing ambivalent feelings which resulted in siblings having confused feelings about their experience. Atkinson and Crawford (1994), quoted the Children Act (1989) and pointed to the failure of local authorities to fulfil their obligations to 'children in need'. *'Community based help'* they argue, *'for these families is still limited'*. (1995:9)

Whilst the issue of young carers has enjoyed a higher profile in the 1990's the focus of most research has been on young people caring for older parents or relatives, (see Tucker and Liddiard 1998), and whilst the siblings in the Northern parents study were not classed specifically as carers it was evident from parent's responses that many siblings were performing caring tasks for their disabled sister or brother. The study did not attempt to quantify the degree of care provided by young carers but it was evident that the care they provided contributed to the totality of the families input. It was evident from the Northern parents that older siblings provided a range of support, particularly in relation to leisure activities. Work on young carers by Becker et al (1998) and Dearden and Becker (1995), accords with instances in the findings from the Northern parents which identified that, for example in one instance, as the younger siblings became physically stronger they were beginning to assist their parents in tasks such as lifting. A telling finding in the study was that such was the sense of obligation felt by some siblings, that they felt they had a long term obligation to care for their disabled sister of brother, almost, it seemed, a life-time commitment.

However, if research has tended to neglect the views of siblings then it has been equally guilty of paying little attention to how parents themselves felt about the effect that caring for their disabled child had on their other children. What the Northern parents identify is that they feel that their non disabled children are disadvantaged and that resulted in mothers, particularly, expressing a degree of guilt. This, of course, fits with ideologies of motherhood, discussed above, and links to social expectations of women as carers, (see Lister 2000). Although the problem has been clearly identified, mothers in the Northern parents saw no solution to the dilemma it created.

A further, and in this section final, factor which has concerned researchers, are the consequences caring for a disabled child have on relationships and the reportedly higher than average incidence of marital breakdown.

The impact of caring for a disabled child on parents' relationships

The common perception is that parents of a disabled child experience greater marital dis-harmony resulting in higher levels of relationship breakdown, Gordon et al (2000), Quine and Pahl (1985), Smyth and Robus (1989). Although Philp and Duckworth expressed some ambivalence in their review, in which they concluded that:

> 'The proportion of parents of children with disablement who become divorced shows considerable variation between studies.' (1982:30)

A difficulty with endeavouring to say that marriages break up as a result of the pressures induced by caring for a disabled child is that it is impossible to establish whether or not a relationship would have been sustained without the presence of a disabled child. Smyth and Robus (1989), pointed to higher levels of breakdowns and separations amongst parents caring for severely disabled children, than in the population as a whole. However, given that this

is an extrapolation from a sample, albeit a substantial one, care still needs to be exercised if parents caring for a disabled child are not to be pathologised as constantly being on the brink of breaking up. An interesting point made by Gordon et al (2000) in their re-analysis of the 1985 OPCS data, is that whilst the data pointed to a higher level of disabled children living with one parent, this did not necessarily denote that there was only one adult in the household. In a number of instances, Gordon et al concluded, there is often one or more adults in residence apart from the parent. These ranged from adult relatives to older siblings of the disabled child, and although this does not imply that mothers have to provide less care and assistance for their disabled child, it does suggest that it would be hasty to conclude that living with one parent automatically means that that parent is the lone adult providing care. However, that apart, for the Northern parents stress attributed to the pressure of caring for a disabled child had, in some instances, been seen as a contributory factor in marriage breakdowns. However, it was never seen as the sole reason and those who mentioned it were careful to highlight that there were existing difficulties with the relationship. However, what does appear to be sustainable is that amongst parents of disabled children, who have had marital difficulties, the degree of impairment has significance:

> 'At a population level, however, the weight of the evidence is that the risk of marital breakdown is greater when a child is disabled and rises with the severity of disability. The difference is not dramatic.' Baldwin and Carlisle (1994:26)

Whilst the conclusion that the severity of a child's impairment has significance when marriages are under stress, there is sufficient agreement, albeit qualified, that when parents are caring for a disabled child there is the potential for greater strain to be placed on their relationship.

However, within relationships, as mentioned above, some elements are under the control of individuals, parents and families, whereas others are extrinsic to the family. These relate to factors such as support offered by statutory

agencies, viz., social services, which in turn free mothers to enter paid employment or pursue personal objectives. Consequently, a reason for higher levels of relationship breakdown, accepting the provisos identified above, could be the inability of mothers to enter the paid labour market. The opportunity to work can be seen to have implications for the economics of a family with a disabled child, so the next section will consider the financial cost of caring for a disabled child, along with employment opportunities for mothers of a disabled child. Notwithstanding the general evidence the level of breakdown amongst the Northern parents appeared to be lower than that highlighted in the research. Given that stress has been cited as a significant factor in relationship breakdowns it is safe to conclude that, if the emotional support the Northern parents identified as gaining from staff at the special schools, then the attendance of a disabled child at a special school could be said to be a contributory factor in lower levels of relationship breakdowns.

Financial costs and employment opportunities

If there is an element of equivocation in conclusions based on research relating to the issues discussed above, this does not extend to the financial costs of caring for a disabled child. For two decades research, Baldwin (1985), Baldwin & Glendinning (1982, 1983), Baldwin & Gerard (1990), Beresford (1994a, 1994b), Dobson and Middleton (1998), Gordon et al (2000), Meltzer et al (1989), Philp and Duckworth (1982) , has consistently identified that, firstly, caring for a disabled child necessitates extra family expenditure and, secondly, that expenditure has to be found from family incomes which are restricted because of limited access to employment for mothers. This is summarised by Graham thus:

> 'The needs of their [mothers] disabled child mean that more is spent on food, fuel, transport, clothes and shoes, and durable household goods such as washing machines (Baldwin, 1985). While spending more than

other families, the incomes of households with a disabled child are typically lower (Smyth & Robus, 1989).'

and

'Only a minority of women with disabled children return to work. As their children get older their employment profiles diverge more and more sharply from those of other mothers with school-aged children.' (1993:119)

The employment opportunities for mothers of disabled children, relative to the general population, have consistently been shown by Hirst (1985, 1992) to be inferior:

'Mothers of pre-school children are very unlikely to go out to work but, as children grow older, the chances of having a job accelerate; mothers of teenagers are almost as likely as women with no children to be in paid employment.

Whatever the age of their youngest child, however, fewer mothers with a disabled child, compared to their counterparts in the general population have a paid job.' (1992:87)

Furthermore:

'Mothers with a severely disabled young person were less than half as likely to go out to work as mothers in the general population.' (Ibid:95)

A study in 1998 by Kagan et al considered the experiences of parents of disabled children who were managing to work. The experiences of these parents confirmed earlier findings and while they were coping with work it was often against the odds. Summarising the views of parents in their study they concluded that:

'All the parents say they need to work for both financial and psychological reasons. Their incomes are important for the families well-being. Welfare benefits do not fully compensate for the costs of disability and loss of earnings.

> Furthermore, even minimal involvement in paid work provides additional sources of satisfaction and esteem, and helps parents to feel that they are active citizens and not just recipients of benefits and services.' (:6)

Kagan et al's findings highlight the dilemma faced by parents of disabled children. As has been demonstrated when mothers, in particular, are able to work it is often for lower pay than they would otherwise be able to earn. Additionally the considerable effort taken to organise care and to meet the additional demands created by having a disabled child, such as increased hospital appointments, requires great effort on their part. Kagan et all did find that there were supportive employers and when this was the case mothers and parents felt less stress, however, in many instances obligations had to be met by being flexible. The need to feel a valued citizen and how this is achieved through employment, links to John's (1988:24) view that disabled people themselves, also gained status through employment. Notwithstanding, the findings of Kagan et al (1998), the generality for mothers of disabled children is that they have fewer opportunities to enter employment.

Nothing the Northern parents said contradicted any of the above findings. Few mothers worked and even fewer had full-time jobs and, although parents were not asked specifically about their financial status it would be safe to conclude that, in most instances, they were likely to be financially less well off than their peers.

An interesting difference to the above can be deduced from research conducted by Chamba et al who found that amongst minority ethnic groups:

> 'Within two parent families less than half the fathers had full-time work, but in most cases parents did not believe that the disabled child had affected the father's employment status.' (1999:4)

The proportion of fathers in full-time work is noticeably different to that of the Northern parents. All fathers amongst the Northern parents were in full-time

work unless they were retired, absent from work due to ill-health, or self-employed. This is a reflection of the general disparity between the employment levels of white males and ethnic minority groups. Within the Northern parents there were only two non white fathers, one had retired as a consequence of his own disability, the other was a consultant physician. However, it is not suggested that generalisations can be made from these particular research findings, but the findings point to differences which are worthy of note.

This chapter has so far identified that the experiences of the Northern parents have many similarities with research that has been conducted over the last three decades. Despite reports and legislation, set against a burgeoning rhetoric for the abolition of special schools for disabled children, the position of parents caring for a disabled child at home has not changed to any great extent. The following section will, therefore, consider relevant aspects of social support.

SOCIAL SUPPORT

It is perhaps hard to understand why the situation for families of disabled children has remained so problematic. In the light of the research findings highlighted above, which span more than two decades, it would be reasonable to hope that social policies would have developed to counter the difficulties experienced by families with a disabled child. Hirst offered the following comment on the situation:

> 'Carers' needs, however, are rarely taken into account by policy makers, service planners and practitioners, In consequence, conflicts of interest between a dependant and carer may invariably be resolved at the expense of the latter. To address this issue there needs to be a serious debate about how support for carers, including social security provision, interacts with community care policy for disabled people.' (1992:100)

Since Hirst's research was published several pieces of legislation have been enacted which containe key elements designed to resolve many of the problems faced by carers. Those problems largely being related to having to provide high levels of care which, as identified above, impact on the ability of individual carers to participate fully in social, creative, and paid activities. Equally, as the study demonstrated, in the absence of adequate social support from recognised agencies, such as social services, support may come from other quarters. In the instance of the Northern parents, an acknowledged source of emotional and practical support came from special schools run by a charity. However, when one considers the accounts of the Northern parents and research such as that produced by Beresford (1995), Chamba et al (1999), and the Joseph Rowntree Foundation's (JRF) 'Supporting disabled children and their families' programme of research initiatives, it is not surprising that 'care in the community' is known, by some, as 'care by the community.' Those aspects of policy relating to support for families caring for a disabled child exposed in earlier discussions will be considered.

The Chronically Sick and Disabled Persons Act 1970 (CSDP) should have enabled families to obtain whatever aids, equipment or adaptations assessed as being appropriate for the care of their child. Information should also have been available so that families were aware of what their entitlement was. This act was hailed as a landmark piece of legislation which recognised that the needs of disabled people should be met, on the basis of assessed need, rather than rigid, standardised processes determined by service agencies. However, the act failed to live up to it's early expectations with explanations for the failure resting largely on the lack of resources made available by central government to enable local authority social service departments to meet their obligations under the Act. Additionally, the introduction of the CSDP Act coincided with the introduction of social services departments and new local authority administrative areas, following on from the Local

Government Act 1971. All these factors combined to relegate the CSDP Act to a lower order of priority.

The Disabled Persons Act 1986 was largely intended to make up for the weaknesses in the CSDP Act and should have, amongst other elements, given rights to an assessment of need and the provision of information. However, this act was not fully enacted. The Social Services Inspectorate found that:

> 'The implementation of Sections 5 and 6 of the Disabled Persons Act 1986 was generally weak and SSDs' involvement with disabled young adults frequently came later than users desired.' (1995a:46)

Sections 5 and 6 refer to procedures which should be adopted when a disabled young person is due to leave school. A key transition for parents of a disabled child and therefore, as has been identified above, also a trigger for higher levels of stress.

Two major pieces of legislation, in the form of the Children Act 1989 and the National Health Service and Community Care Act 1990, had at their core the need for an integrated approach to providing services for disabled children and their carers. Guidance and Regulations associated with the Children Act 1989 set down the duties of SSDs:

> SSDs have a clear, positive and separate duty to provide services to children with disabilities in their area. SSDs developing policies for children with disabilities within the overall framework of the Children Act should ensure that they have a specific policy on integration of their services which meets their general duties and powers towards children and families under the Children Act. Policies should take account of the wishes and views of the local community including user groups. Every effort should be made to work collaboratively in team and multi-agency structures in order to avoid the creation of separate and segregated services.' (:2)

Adherence, by SSDs, to the guidelines would have led to less overlap, duplication, and confusion which would in turn have lessened one of the main cause of stress for parents, JRF November:1999.

Similarly the NHS & CC Act 1989 stressed the need for planning services. The SSI (1997) recommended that:

> 'Making community care a reality for people with complex needs, however, demands particularly intensive and sensitive service planning, targeting and development.' (1995; Appendix A)

It is evident from guidance and reports that there is agreement on what needs to be done to make caring for a disabled child or young person easier for the parents. Unfortunately successive reports have observed that the reality falls short of the promise. The SSI (1994) found that:

> 'No evidence was seen of effective co-ordination of assessments for disabled children under different legislation.'
>
> 'Very little comprehensive information was produced for disabled children and their families, and very little of that was translated into community languages or available in other media.'
>
> 'None of the authorities inspected were operating an effective register of disabled children.....However, at the time of the Inspection the lack of a register, or alternative comprehensive up to date lists, had resulted in there being no reliable current information on the numbers, nature and distribution of disabled children in those authorities.' (:5/6)

The Audit Commission (1994) also found that:

> 'The Commission's survey, however, indicated that parents were unhappy with the amount of information and advice provided, particularly when an impairment was first diagnosed. Parents with older children also felt a particular lack of partnership with health and social services when it came to coping with the additional problems attending adolescence. Three

quarters of all parents with teenage children in the survey raised this as a significant issue.' (:27)

The report also concluded that:

> 'Overall, however, there was little evidence of inter-agency co-ordination at a strategic level, which is perhaps not surprising given the complex system of functions and referrals and the lack of coterminality between health and social service authorities.' (Ibid)

Collaboration and co-operation seem, on the evidence, Audit Commission (1992, 1994), SSI (1994, 1995b), JRF (November 1999), to be as elusive as they ever were. But, to add to the need for collaboration between health departments and social service departments the Education Act 1993 stiffened the Education Act 1981. With the 1993 Act came a 'Code of Practice' which laid down how the Act should be implemented. The 1993 act included reference to relevant aspects of the Children Act 1989 in relation to joint assessment and collaborative working, and also stipulated responsibilities for District Health Authorities. They should:

> 'consider with the LEA and relevant social services departments how to collaborate in meeting their joint responsibilities under Section 27 of the Children Act 1989 and Section 166 of the Education Act 1993.' Bentley et al (1994:33)

It is hard to imagine that if SSDs and Health Authorities were not able to develop collaborative working strategies, then they would be equally unable to develop joint working with a third statutory body, not to say independent providers also. However, there are examples of how agencies can work collaboratively with research by Mukherjee et al (1999), showing that key working offers one solution, if it is supported fully by managers in service providing organisations and not left to the individual key worker themselves to implement. Indeed the JRF 'Supporting disabled children and their families' programme highlights examples of good practice, but they remain relatively isolated examples and do not, as yet, indicate that a general shift in approaches to supporting families caring for a disabled child is taking place.

It is evident that there is a correlation between the needs of parents, both those highlighted in the literature and the Northern parents, caring for a disabled child or young person at home and the failings in service provision identified by successive reports. On the one hand parents cannot obtain sufficient information on their entitlements or available services, nor do they receive adequate support, Additionally their statutory right to an assessment is not being met. On the other hand statutory agencies fail to meet their obligations across a range of statutory instruments and legislation. Additional legislation has been enacted which place further duties on local authorities and other agencies. Namely, the Carers (Recognition and Services) Act 1995, and the Disability Discrimination Act 1996. However, there is little prior evidence to suggest that these two pieces of legislation will be any more effective in ensuring that parents of a disabled child obtain the services to which they are entitled, inadequate though they might ultimately prove to be.

There are other factors which impinge on the lives of parents caring for a disabled child or young person, notably Social Security Benefits which Kagan et al (1998), established were inadequate and inflexible when parents with disabled children endeavoured to work. They concluded that:

> 'Benefits do not compensate for loss of earnings when parents reduce their working hours, nor for the cost of care. The earnings thresholds on benefits combined with the difficulties in sustaining secure but flexible employment traps many families in poverty. It is difficult to obtain information about benefits and pressure is created for parents when they have to complete full and detailed assessment forms repeatedly. Current proposals for welfare to work initiatives will need to fully address the complicated circumstances of lone parents with disabled children' (1998:41)

The pattern of poor information identified in reports on the provision of community care for disabled children and their families is repeated by the Benefits Agency which further emphasises the need for information on all aspects concerning parents caring for a disabled child or young person to be

collated and provided by one centralised body. Issues concerning social security benefits are more complex than the representation of the views of parents of a disabled child endeavouring to sustain employment alone. It is that very complexity which militates against a more detailed analysis. Therefore, the findings of Kagan et al (1998), are intended to serve as further underpinning of failings in social policy. Deeper analysis might skew the discussion away from the main theme of providing support and care, of which social security benefits are an integral part, but one of a number of interlinking components.

SUMMARY

The aim of the study conducted with the Northern parents has been clearly stated as being to establish why that particular group of parents had chosen special education for their disabled children. Results generated by the survey questionnaire indicated that factors beyond merely the provision of an education would provide information leading to the possibility of formulating an explanation for the choice. So it was, that the twenty-four interviews conducted with the Northern parents revealed that there were many factors impinging on their lives which offered a rationale behind their choice of a special school. Those factors penetrated many facets of their lives and touched on key life events, from the disclosure that their child had an impairment, through the process of caring for and raising their child into adulthood, to concerns for the future facing their disabled child. The purpose, therefore, of this chapter was to locate the particular, and unique, experiences of the Northern parents, within pre-existing knowledge. The body of literature relating to disabled children, families with a disabled child, mothers caring for a disabled child, and the experiences of parents who have a disabled child, has grown over the last three decades as the loci of care has moved from being predominantly provided in residential institutions, to being

provided by parents in the family home. And so it was that the experiences of the Northern parents had many similarities with those of parents featured in other research, whilst there were also elements of difference. This summary will now bring together the key themes and point to why these offer an explanation for parents' choice of a special school.

A significant aspect of the lives of parents of disabled children has consistently been shown to be their relationship with professionals in the field of health, education, and social work. The literature confirmed that this aspect of the Northern parents' experience was not unique and that relationships with professionals had an immense significance on important events in their lives, as well as on their day-to-day existence. This was epitomised by the process surrounding the disclosure of their child's impairment. These earliest contacts with the medical profession formed the basis for subsequent attitudes towards professionals. Medical professionals, predominantly doctors, were seen as generally dealing with what, for parents, was a distressing and traumatic event, with a lack of sensitivity and, seemingly, a lack of awareness of the impact they were having on parents. An exploration of ideologies of motherhood, established why this might be so, in that the message is conveyed that mothers have achieved the ultimate height that any women could wish for, if their baby has no impairments. The discourse of motherhood then presents the birth of a child with an impairment as a failure. This is translated into a model premised on the notion that to give birth to a baby with an impairment is to experience the 'death' of the baby that was expected. The view that parents have suffered a loss was shown to shape subsequent professional attitudes to mothers in particular, and parents in general. The result being that parents were characterised as 'heroic' and mothers pathologised as 'tragic' figures martyring themselves for their disabled child. This, however, was certainly not how parents saw themselves with this view lacking support from either the Northern parents or contemporary literature. Rather the Northern parents, as with other research studies, could be identified as doing what a parent would do for any child and

getting on with it one-day-at-a-time, in a pragmatic, realistic way, yet caringly and with love.

Despite the results of research there was still sufficient evidence to suggest that the medicalisation of disability and disability as a 'tragedy' persisted in professional relationships as children grew older. However, the view of mothers as heroic martyrs changed into one of mothers wishing to keep their disabled child in a state of eternal childhood to gratify their own emotional needs. The Northern parents did not exhibit such an emotional state but rather saw what they were doing as something that could not be supplied from any other source. Consequently, they found themselves having to adopt, the role of advocate for their disabled child, and to mediate between them and the unthinking attitudes of other people, the consequences of structural inequalities, and institutionalised injustice.

It was argued that professionals will place parents in different roles depending on the setting they are in, or the goals they feel parents can achieve. These were shown to be the view of mothers as being essentially always 'good mothers' and, therefore, able to carry out medical regimes as instructed by medical professionals. On the part of social work and social care professionals, parents were seen as having the capacity to further programmes designed to modify behaviour or develop skills. Therefore, parents would be embraced by professionals in the spirit of partnership. Although, it was demonstrated that the level of social support and contact with social service departments experienced by the Northern parents, was matched by the majority of research findings. The experience was personified by a marked inadequacy of support services and a low level of contact with agencies charged, under legislation, with the responsibility of providing support for disabled children and their families.

The impact of having a disabled child was shown to have myriad consequences for families. The Northern parents identified how they felt

other children in the family were affected. This was identified as a neglected factor, although recent research on young carers matched some aspects detailed by the Northern parents, whereby siblings were providing a degree of physical support for their disabled sister or brother. This role extended into, in some instances, an extension of the obligation mothers felt to provide extended care for their disabled child when they became adults, inasmuch as some siblings felt they should be responsible for their disabled brother or sister *sine die*.

Caring for a disabled child was considered to be the cause of a higher level of marital and relationship breakdown. However, this was seen by the Northern parents as being a contributory factor, albeit a significant one, where relationships had broken down. There was, however, universal agreement that caring for a disabled child resulted in higher levels of stress and caused anxiety for parents. Be that as it may, the cause of stress was found not to be solely the result of caring for a disabled child, but rather as a result of structural factors. These being, predominantly, the inability of agencies to provide adequate and appropriate support to families. The inadequacy of support had a number of repercussions, mostly for mothers and, whilst families caring for a disabled child were shown to spend three times as much on raising their disabled child, social security benefits do not compensate for the gap between income and expenditure. Further repercussions were that mothers found that they were unable to return to paid work and earn additional income and were, to a large extent, excluded from mainstream social activities. Comments from mothers in the Northern parents, supported by published research, confirmed that they become isolated from their peers.

The picture from the Northern parents, and the literature, was that parents caring for a disabled child have markedly different experiences to those of their peers who do not have a disabled child. The major disparity was in the quality of life experienced by mothers. Mothers are expected to provide the necessary care for their disabled child and, furthermore, mothers feel that

they will be obliged to continue providing support well into their child's adult life. Despite a volume of legislation designed to provide support for disabled children and their families, parents are consistently shown to be coping on their own with little, or no, support from statutory agencies. The accumulated consequence of these circumstances is that parents caring for a disabled child have lower incomes, fewer opportunities, poorer health, and are categorised as carrying a burden, rather than bringing up a child with some differences. What differentiated the Northern parents from the bulk of the research discussed above was that, for them, some of the shortfalls highlighted in the literature, were being met by special schools.

The literature highlighted the need for stability so that parents could get on with their lives. The Northern parents, having, like many of the parents identified in the literature, battled with authorities to get what they felt was best for their disabled child, felt secure in the knowledge that the special school would not cause the problems many of them had faced with mainstream schools. Furthermore, mothers did not have to make as many clinical visits because services were provided on the school site. Therefore mothers could achieve some time for recuperation. Additionally, whilst parents uniformly identified the need for some form of counselling service, the Northern parents received emotional support from staff at the special school which, they considered, helped them to manage the other demands associated with caring for a disabled child. An absent need, highlighted in the literature, was found by the Northern parents to be a further advantage to being connected to a special school, this being: information. Research studies have repeatedly shown that parents are not provided with sufficient information on social security and other benefits, entitlement to services, and generally useful tips. This should be provided by social services departments, but, invariably, it was not. The Northern parents found that the informal links with other parents and information sessions provided by the special schools, enabled them to learn far more than they did from other sources. It is evident, therefore, that whilst the experience of the Northern

parents has many similarities with other parents caring for a disabled child at home, the choice of a special school alleviates some of the pressures identified in research on the experience of parents of disabled children in general. However, it has been shown that the choice of a special school cannot be seen as uncontested, so, the decision needs to be considered within a wider social and political context. Therefore, whilst this chapter has placed the experiences of the Northern parents within a wider context of families caring for a disabled child, the next chapter will locate the choice of a special school within debates on inclusive education and issues allied to the politics of disablement.

Chapter 5

Culture, Identity, Disability Politics and Consumerism: Special Education in Context.

INTRODUCTION

Previous chapters have considered different aspects relating to the experience of parents caring for a disabled child, with the objective of finding out why parents choose special education. Whilst this analysis has offered a reason for the choice, this being that, predominantly, parents get support, information, and security; from school staff, other parents, and ancillary activities which they would otherwise be unable to access. This choice has been positioned within the debate around the inclusion of all children in mainstream education. Consequently, the choice of a special school occupies a contested political a244rena which sees special education as segregating disabled children from their non-disabled peers which, it is argued, causes disabled children to acquire a negative self image and a 'second-class' identity. Nevertheless, special education endures so, if order is to be given to the debate on inclusion, and the consequences attributed to parent's choosing special education, the different elements comprising the context within which special education exists need to be critically discussed. This chapter will, therefore, provide detailed analysis of the debate on inclusive education as represented by the view of the disability movement and the education profession. This will include the key issue of defining disability. The social model of disability has been referred to a number of times in earlier chapters, notably as an alternative approach to the individualisation or medicalisation of disability. The social model will be critically analysed, and contemporary debates on the capacity of the social model to fully

accommodate the complexities that being 'disabled' incurs, will be discussed. The discussion will feature what has become a significant issue for disability activists and theorists, namely, the concept of disability as a distinct culture and identity. The discussion will be located around the notion that to be disabled is to have a particular cultural identity which, it will be argued, needs to be promoted unless disabled people are to run the risk of social homogenisation as merely being a 'social construction'. Within this debate, it will be shown, special education is both seen to be playing a key role, and also needs to develop a role in positively promoting the cultural identity of disabled people.

However, having explored the inclusionist debate and the issue of disability as a cultural identity, the discussion will move on to explore how the two issues relate to choice. The concept of choice, it will be argued, has arisen as a consequence of a shift in political ideologies which see users of public services as consumers. The result of this is that a discourse has evolved within, and around, the provision of services which places the notion that service users have choice, at the forefront of policy statements and related rhetoric. It will, therefore, be proposed that there are inherent contradictions in the differing concepts so that inclusive education policies challenge the notion of choice and the developing concept of disability culture. It will be shown that a reconciliation of the three concepts will be problematic within current policy objectives and that the abolition of special schools will not serve to resolve the inherent contradictions but may, it will further be argued, only serve to exacerbate the differences. Furthermore, the position of parents within the triumvirate as 'consumers' is shown as being contentious, so that the choices available to parents of disabled children, and the scope they have to exercise choice, need to be given clarity if the choices parents make, for their disabled child, are to be understood, not just as an individual choice, but as a choice which takes place against a background of unresolved debate and developing concepts.

So, the discussion will commence with an exploration of the significance of how inclusive education is defined.

INCLUSIVE EDUCATION

Defining inclusion

Earlier chapters have referred to education as being 'special', 'segregated', 'integrated', or 'inclusive'. Whilst these terms may, superficially, appear to have distinct differences, a closer examination of the changing terminology applied to where disabled children receive their education will reveal that the terms represent more than a mere explanation of their meaning would indicate. This section will, therefore, discuss how different terms have come into usage, and the pejorative meanings that can accompany their use.

Several adjectives have been used to define education which is not divided on the basis of factors such as class, gender, ability, race or impairment. The most popular term in contemporary usage defines non-segregated education as being 'inclusive'. However, immediately prior to the adoption of the term 'inclusion' in the early to mid 1990's, the sole term in popular usage since the late 1970's had been 'integration'. As a result of the initial use of the singular term 'integration' and the subsequently dual use of that and 'inclusion', a number of references will be featured which appear to be crediting the terms with equal meaning. This is a representation of the chronological development of the debate on inclusive education. The adoption of the term 'inclusion' can be seen as being, largely, the result of a discreditation of integrative practices and its association (Reiser 1997), with the medical model and its adherence to a concept of individual deficit. Educational approaches which see children who require strategies to enable them to learn as being

'problems' or having 'difficulties', is a vexed issues and has prompted Booth (1997) to argue that:

> 'the language of special needs and learning difficulties is used in a confusing and contradictory fashion and that clear thought with it has virtually ceased.'

Furthermore, Booth continues:

> '....the language of 'special needs' cannot be rescued.'

Notwithstanding, he continues:

> 'However I will claim that we have no choice, given the ordinariness of the terms to continue to struggle with the notion of 'difficulties in learning', that we can reappropriate it, and provide social or socio-personal models of difficulties in learning that can be made adequate.' (unpublished discussion paper March, 1997)

Booth is not the only writer to comment on language, Corbett also refers to problems with 'political correctness':

> 'Our current terminology and attitudes have changed in that they illustrate a heightened degree of sensitivity and an awareness of the delicacy and controversy of many issues. Yet I fear there is a danger that this element of political correctness in special educational language is but surface deep. Underneath, the weight of redundant thinking holds back radical changes in service provision which are required if client-led needs are to determine practice.' (1994:19)

The fear that educators and policy makers merely adhere to a use of terms which become contemporary professional jargon, rather than being committed to the philosophy which underlie their emergence, is shared by Booth:

> 'A concern with overcoming barriers to the participation of all in education is captured, for some, by the notion of 'inclusive education'. This term has acquired increasing international currency which poses the danger that wishful thinking about the way it is used or applied may distract people from exploring the realities of practice.' (1997:3)

Both Booth and Corbett appear to share the view that the use of 'correct' terminology does not, in itself, denote a change in the reality of current educational provision. The distance between the rhetoric of inclusion and the reality of educational provision was highlighted in earlier chapters and will continue to surface as an issue. Nevertheless, whatever opinions there might be on the use of language we are inhibited, when analysing current positions on non-segregated provision, by the terms in popular use.

So, an exploration of the differentiation between 'integration' and 'inclusion' will identify how the debate on inclusion has developed in recent years.

The two terms are seen as representing different ways in which children seen as having special educational needs have had their needs met within mainstream education. Integration is seen to represent approaches linked to separate provision, such as support units within mainstream schools which, whilst being located on the same site, still segregate children with special needs from their able bodied peers. This is exemplified by Alderson and Goodey who, whilst conducting research on the provision of education for children with autism, identified the following:

> 'The unit observed is, in theory, part of the adjacent mainstream primary school, and shares the site also with a mainstream secondary and a large special school. There is almost no contact between the schools, they might as well be miles apart.' (1999:262)

This is the epitome of what inclusionists see as exemplifying integrated approaches, whilst inclusion, on the other hand, is seen to represent a completely non-segregated system. This discussion on terminology begins to highlight differences in approaches to the education of disabled children in mainstream schools, and adds further to the view that professionals can indulge in, what can be seen as largely theoretical debates, which may obscure key issues from lay people, in this instance, parents of disabled children. And while language does have a significant part to play in the

debate on inclusive education, it provides a cogent introduction to the fundamental debate on inclusive education. The section will now continue by exploring, in some detail, that debate.

Educating disabled children and young people

The following discussion develops the debate on where, and to some degree how, disabled children should be educated, by identifying key strands in the debate and the positions of the main protagonists.

Booth defines inclusive education as:

> 'An education system which values the diversity of its students as a human and cultural resource is one in which education takes place in common, comprehensive schools and colleges, in which there is the minimum of separation on the basis of competence and appearance.' (1992:3)

Nevertheless, despite the acceptance by policy makers, albeit, contained within legislation couched in language allowing for avoidance, the adoption of non-segregational schooling is not without opponents prepared to state their opposition, as Barton points out:

> '.....integration is controversial. It is a topic associated with deep felt emotions and heated debates. It raises profound issues far beyond merely educational concerns and is ultimately directing attention to the question of the nature of society.' (1989:1)

The 'nature of society' referred to by Barton alludes to previous discussions which argued that people with impairments have a negative and secondary status in society. Inclusion, therefore, is seen as a crucial way of challenging a notion which has prevailed in modern western societies. One concept, that disabled people are a 'threat to society', is seldom voiced in relation to children as a justification for segregated provision. Rather, the justification

tends to be couched in more beneficent terms, such as those expressed by Forman and McCormick:

> 'In the best circumstances, special education would provide students with a new community that enables them to experience a greater degree of success. In other words, within the community of special education, these students would be able to move toward full participation in the community's practices. Ideally, the conditions for the negotiation of meaning within the special education community would be better adapted to the needs of these students so that they could master at least some of the discourse practices, tools, and beliefs valued by the general education community.' (1995:154)

The stressing of the idea of 'community' epitomises this stance because it highlights the notion that disabled people have a shared discourse and, therefore, their specific needs can best be met within a shared discourse. The assumption being that disabled people share a discourse of their own cognition. However, this is belied by the assumption that by being part of their 'special' community they can best learn what is required by the 'general education community' thereby dispelling any notion that disabled people should do anything other than assimilate with the non-disabled discourse of education. Furthermore, the discourse espoused in the name of community has a language based on professional elitism and a medical model of disability. Therefore, parents are largely excluded from the discourse because they lack the expertise, although, as Chapters 3 and 4 identified, parents can learn the language and challenge the inherent assumptions contained within the discourse.

A view which represents that expressed by inclusionists is put forward by Slee:

> 'The central argument embedded within this discussion accepts a view of inclusive education as a recognition of schooling as a site for cultural politics where disabled students are not the objects of assimilation. Inclusive schooling for disabled students embodies the challenge of expressing the full range of human variation in school cultures which are mediated through curriculum,

pedagogy and school organisation. According to this perspective the grafting of traditional special educational practices and additional material and human resources onto the existing school will reinforce the legitimacy of existing cultural relations and the marginal status of disabled students.' (1997:409)

This view argues for the inclusion of the identity of disabled people within a wider cultural context which will enable disabled students to develop a clear cultural identity, that of a disabled person, and also re-define existing cultural practises within education. This, however, it is argued, will not be achieved by merely abolishing special schools because existing modes of thinking and teaching will just be absorbed into mainstream schools. The consequence of this would be the perpetuation of existing discriminatory attitudes towards disabled people. Therefore, for inclusion to be effective a wholesale change is necessary in the organisation of schools and colleges.

Slee refers to schools as being sites for 'cultural politics', therefore, leaving aside for the moment the issue of disability culture, if disability culture is absorbed into the general curriculum then, ultimately, inclusion will enable disability to be seen within a cultural context rather than being seen as a personal deficit. However, the idea that mainstream schools provide the best site for 'cultural politics' is contested and will be discussed more fully below. Slee's view, as with that of Forman and McCormick (1995), are based on recognising difference and either dealing with it in a separate setting, or by using schools to proselytise the future adult population, implying that disabled students would be at the vanguard of the new movement.

The above are examples of some of the different positions referred to earlier, and come from within the education profession. However, the most vocal position is that held by those who advocate the wholesale introduction of an inclusive system of schooling. They occupy a broad church but, for the purpose of this discussion, those occupying that position will be referred to as 'inclusionist'.

Within that broad church inclusionists could be crudely placed into groups comprising professional educators who believe in full inclusion, such as Booth, who defines his position thus:

> 'When I discuss integration in education, for example, I have a wider group in mind. Besides young people with disabilities I think of all those who experience difficulties in education. I would argue that thinking about integration in this way makes it a concern for all those with a stake in education.' (1992:24)

Alongside education professionals and education theorists there are parents of children who have been defined as having special educational needs. Representative of this view is the following extract from a factsheet produced by the Centre for Studies in Inclusive Education (CSIE):

> 'Support for the principle of integration in education rests on the right of people with disabilities or difficulties in learning to the same opportunities for self-fulfilment as other people.' (1996:1)

Both the above groups see equality of education as being the right of all children whereas the last group see education as being part of a wider goal.

The final group comprises the disability movement. The disability movement has at its core the principle that the full inclusion of disabled people into society is a fundamental civil right. Inclusive education is, therefore, just one aspect, albeit a significant one, of social inclusion. The disability movement's commitment to inclusive education is largely based on a historical and personal critique of its failings, as Oliver argues:

> '....that the education system has failed disabled children in that it has neither equipped them to exercise their rights as citizens nor to accept their responsibilities. Further, as I have already suggested, I will argue that the special education system has functioned to exclude disabled people not just from the education process but from mainstream social life. (1996:79)

That, then, is a summary of the stances taken by the main groupings in support of inclusive education. Education professionals and parents seeing inclusive education from the standpoint that all children have the right to be

educated alongside one another. This view is underpinned by the belief that it is every child's human right to receive an education. The disability movement differs slightly by approaching inclusive education from the empirical standpoint that evidence shows that segregated education is responsible for producing generations of disabled people who have not participated fully in society. As a consequence it is the civil right of disabled people to be educated inclusively with their peers. That said, the discussion will now move on to consider these positions in more detail and will develop further the differences, hitherto hinted at, between the groupings, by exploring the nuances of the different stances, both between and within them.

Stances on inclusive education

Without wishing to generalise it would be true to say that the loci of the debate on inclusion is within the education profession itself. There are alliances with groups outside the education profession, such as the Integration Alliance and the Centre for Studies on Inclusive Education, but the thrust for inclusion lies predominantly with education professionals themselves. The debate then, is often conducted in professional journals and within the framework offered by professional trade unions. In contrast to this the CSIE, for example, aims to stimulate change and as one thread of its activities publishes material aimed at school management which is designed to offer guidance and advice on legal obligations, and how to implement them at the level of the 'ordinary' school. An example of this is the CSIE's Guide to Developing an Inclusive Policy For Your School. In the introduction the guide states:

> 'Inclusive education also demands that ordinary schools change their systems and structures for educating and socialising children and young people. Adaptations to the school curriculum, the buildings, the language, images and

role models in the ordinary school are some of the changes required to make inclusion work.' (1996:4)

Implicit in this statement is the way in which inclusion is viewed from within education. That is, it is seen as a process which needs to be adopted and implemented in order to achieve the stated common aim. The common aim being the previously stated belief that it is every child's right to be educated alongside her or his peers. However, the continuance of education in segregated settings has prompted discussion.

Commentators on the failure of education to achieve inclusion highlight professionalisation as being one of the major factors inhibiting progress. Fulcher claims that the medical model pervades education thereby individualising problems and developing solutions based on the application of professional expertise.

'Medical discourse *individualises* disability, in the sense that it suggests individuals have diseases, problems or incapacity's as attributes. Finally, it *professionalises* disability: the notion of medical expertise allows the claim that this (technical), and personal trouble is a matter for professional judgement. These aspects of medical discourse are socially powerful: other discourses which are associated with medicine take on these characteristics: this is the case in psychological and educational discourse which, together with medical discourse, have dominated educational practices organised around a notion of disability.' (1989:27)

A consequence of the individualisation and professionalisation of problems is that the solution to problems associated with including disabled children in 'ordinary' schools is to train and improve the skill base of teachers. Hegarty makes this quite clear:

'Integration is in the end a matter of providing appropriate high quality education for pupils with special needs in regular schools. Whether or not this happens depends critically on teacher variables, specifically their willingness to take on this task and their ability to do so. These two variables are interconnected: teachers, like others, are more willing to carry out tasks for which they have the requisite

skills and resources; and the possession of a repertoire of skills likewise engenders the desire to use them.' (1994:125)

The impression given is that there is an acceptance within the teaching profession that all children are entitled to the same education within their local school, this being projected by representative organisations as a 'human right'. However, this can, in turn, be translated as being unachievable and impractical because teachers are inadequately trained and do not have the appropriate skills.

A further complication based on self-interest is introduced by Shirley Darlington, a National Union of Teachers Assistant Secretary, who identifies intra professional tensions as being a potential obstacle:

> 'The tension between the views of members working in special schools, who saw the value of favourable staffing ratios, expert teachers and ancillary staff, and specialised buildings and equipment, and those who favoured integration on ideological grounds were apparent.' (1992:317)

A further facet of this aspect of the debate suggests that professionals have a vested interest in the continuance of specialist provision. Consequently, innovations which ostensibly meet need, are professional definitions of need. As McNight has proposed:

> 'Professionalized services communicate a world view that defines our lives and our societies as a series of technical problems. Thus technical definition is masked in symbols of care and love that obscure the economic interests of the services and the disabling characteristics of their practises.
>
> The sum of these disabling characteristics is an ideology that converts citizens to clients, communities to deficient individuals and politics to a self servicing debate by professionals over which service system should have a larger share of the Gross National Product.' (1981:33)

This highlights a criticism often levelled at professionals by the disability movement, notably by activists and writers such as Oliver (1983), and remains an area of debate which is difficult to prove or disprove.

However, within the above statements lies the nub of the issue for the education profession. Within it, on the one hand, are those who are committed to inclusion as an ideological imperative, and those, on the other hand, who will implement inclusion if it is required of them through policy directives. Accordingly, the strategies for achieving inclusion differ. As stated above one strategy is that of enhancing professional skill and utilising expertise. Clearly this is a solution bound up with resources. Those committed to inclusion on ideological grounds see the solution in the enforcement of legal obligations which would, in turn force resources to be utilised to facilitate the needs of students with disabilities.

A difficulty with the latter solution is that the inclusive movement, as stated above, is committed to inclusive education for all children and not disabled children alone. This means that strategies for implementing inclusion associated with that solution are of a general nature and do not target the needs of pupils with impairments. As Soder suggests:

> 'Ideologies differ from theories in the sense that their primary concern is not how reality is, rather how reality should be. As ideologies are incorporated into the social structures and applied for change, they become more 'simplified' than the theories they build upon. (1992:43)

The implied danger, if one takes Soder's point, is that inclusionists are at risk of subsuming individual need and ignoring the realities of impairment. This could be taken to mean that the blanket belief in inclusion runs the risk of assuming, that every need can be met within the ordinary school; if adequate resources are made available. The question being 'Even with the mobilisation of resources, with all that that means in terms of support and equipment, can every child's needs be met within the mainstream of schooling?'

In keeping with the Disability Movement's commitment to full civil rights for all disabled people this is not a question which would be asked. Rather, the position of disabled people as an oppressed group within society is seen as being a consequence of:

> '...several factors, including the actions of well-meaning, but ill-informed parents, protracted professional intervention, lengthy periods of hospitalisation, segregated special education, and a largely inaccessible physical environment combine to ensure that many disabled children grow up apparently accepting the many economic and social deprivations associated with a conventional 'disabled identity'. Oliver and Barnes (1998:67)

In order to more fully understand the role the disabled peoples' movement perceives special education as fulfilling, a discussion follows which provides sufficient detail to facilitate a grasp of the 'politics of disablement'. A grasp of which are essential if the issues against which the choice made by parents of a special school are to be fully appreciated and, also, to understand the significance of the authors changed position.

DISABLED IDENTITY

Over recent decades disabled people have developed a shared identity based on a 'social model' of disability. The social model has been developed alongside a ground swell of consciousness raising that has seen disabled people forming organisations to represent themselves, and to promote the rights of disabled people. It would be difficult to separate the social model from this consciousness raising because the two are inextricably linked. Additionally, unless the strength of feeling embodied by the disability movement is understood, and the potential impact the movement may make on policy development, then the size of the challenge faced by parents promoting the value of special education cannot be understood. This section will, therefore, commence with a brief explanation of the social model and the

disability movement. The section will then move on to discuss the position of the disability movement in relation to education.

There is a view that the disability movements' origins lie with the collective movements associated with Black Americans and the rise in civil rights movements in the USA in the 1970's. This is contested by disabled people in Britain who point to the efforts of Paul Hunt, also in the 1970's, as being a clear indication that disabled people in Britain had identified the source of their own oppression. The catalyst for Hunt being a research project completed by Miller and Gwynne (1972) which, rather than exposing the oppressive nature of the residential care being provided for Hunt and his fellow residents at a 'home' for disabled adults, only served to perpetuate the oppression by exploiting the access provided to them by using the research to, as Oliver (1990) has argued, serve their own professional academic ends. However, Oliver and Barnes suggest that:

> 'The emergence of the American Independent living movement (ILM) was especially important because it provided both an ideology and a practical solution to the problems faced by disabled people trying to live with inadequate and inappropriate welfare systems.' (Ibid:71)

Notwithstanding the role model of the American movement, the driving force behind the emergence of the British disability movement was the voiced experiences of disabled people themselves. Micheline Mason is representative of those expressions:

> 'As disabled people we have been struggling for a long time to liberate ourselves from the chains of an able-bodied culture which does not value us, and tries to teach us to accept an unequal status in our societies.' (1992:223)

'Unequal status' is the foundation of the struggle of disabled people to achieve equality. Inequality is seen as being perpetuated by institutionalised practises which take no account of the individuality of disabled people, or recognise their needs, and, thereby the devalued status of disabled people is perpetuated and the dominance of able-bodied people over their lives is

maintained. Disability is, therefore, not an individual problem but is constructed through the transmission of a dominant able-bodied ideology. The Union of Physically Impaired Against Segregation, of which Paul Hunt was a founder member, published the following statement which, in over twenty years, has not been improved on as a concise and accurate summary of the cause of disability:

> 'In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. To understand this it is necessary to grasp the distinction between the physical impairment and the social situation, called 'disability', of people with such impairment. Thus we define impairment as lacking part of or all of a limb, or having a defective limb, organism or mechanism of the body; and disability as the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them in the mainstream of social activities. Physical disability is therefore a particular form of social oppression.' (UPIAS, 1976:3/4)

This definition of disability as 'social oppression' has come to be known as the social model.

So, having found a voice and a unifying vehicle in the form of the social model, disabled people began to challenge social practices. The result is that since 1976 the social model has become the engine of the disability movement providing the platform on which disabled people have increasingly voiced their demands for civil rights. One aspect of this has been a growth in disability writing. The significance of which will now be discussed.

Promoting the social model

Prior to the 1980's there was little published in the way of a 'disability literature', however, during the 1980's and 1990's a body of work has

emerged. Much of this has been produced by disabled sociologists who, taking as their rubric the social model, consistently published critiques of social practices. Work by Abberley (1987, 1996), Barnes (1990. 1991), Finkelstein (1981), and Oliver (1983, 1990, 1996), were instrumental in continuing to stress the social nature of disability and to emphasise its extrinsic causality. A recurrent problem with the stress placed on the social model is that the complexities associated with disability, such as identity and culture, are subsumed under what has largely become a historical structural analysis of disability. This is, to a degree, understandable because a feature of the dominant writers of the period, and therefore those most influential in the development of the social model, is that they were academic sociologists, they were white males, and they shared a structural, materialistic and deterministic perspective. Abberley, grappling with 'The Concept of Oppression and the Development of a Social Theory of Disability', identified how a predominantly structural analysis of disability could represent an overly simplistic approach to resolving inequalities. Abberley concluded that:

> '....to usefully apply the notion of oppression to the complex of impairment, disability and handicap involves the development of a theory which connects together the common features of economic, social and psychological disadvantage with an understanding of the material basis of these disadvantages and the ideologies which propagate and reproduce them,' (1996:176)

This quotation is taken from an article first published in 1987. A date which signifies the onset of a period during which the disability movement grew in strength and confidence and began a debate and discussion of the social model of a complexity that went far beyond the need of disabled people for a clear and concise term of reference. Arguably, this need for a concise term of reference has led to criticism of the Disabled peoples' movement, or at least one of its representative voices, the British Council of Disabled People (BCODP), that it is using a social model which is too reductionist. Those criticisms have come from within the disabled peoples movement itself, and will now be considered.

The social model examined

That the social model should prove to be both the pillar of the disabled peoples' movement, and also the object of internal criticism is a mark of a growing sense of confidence by disabled people who feel that the movement is strong enough to withstand interrogation, although this view is not unanimous, as will be seen later. That being said, criticisms are levelled by disabled people who also locate themselves within other oppressed social groups. Examples of these include Susan Peters, a disabled feminist, who, feeling constrained by the social model's singular determinism, writes:

> 'Within the last few years, however, I have felt that something was missing - my sense of self. I began to feel the need to re/define myself as an individual and to validate my personal biography of unique lived experiences in multiple communities - only one of which was my disability network of political affiliations.' (1996:215)

Vernon has added her voice to criticisms of textbooks and discussions on disability by stressing that:

> 'Issues of race, gender, class, sexuality and age have either been omitted as irrelevant to disabled people's lives, or added on as an optional extra.' (1999:390/391)

The loss of the voice of the individual within existing disability discourse has spurred disabled people to look for some accommodation which acknowledges the value and relevance of the social model as a theoretical explanation of the social position of disabled people. One such is Liz Crow who argues for an approach to disability which acknowledges the personal experience that disabled people have of their impairment. Impairments, Crow argues, can also limit an individual's capacity to function, but this does not negate, nor should it detract from, the overwhelming weight of social oppression disabled people experience. Therefore:

> 'A renewed approach to the social model is vital, both individually and collectively, if we are to develop truly effective strategies to manage our impairments and to confront disability.' (1996:223)

So, disabled people are engaging with both theoretical explanations of how their oppression originated and is perpetuated, and also endeavouring to stimulate a revision of a perspective which, for some disabled people, excludes individual experience from its analysis and to seek a 'theoretical synthesis' capable of embracing the complexities discussed above. A further expression of some of the frustrations disabled people feel about the social model's inadequacies are vehemently expressed in the Greater Manchester Coalition of Disabled People's magazine:

> 'The Social Model is all but useless for strategy because it's so abstract, disability is apparently due to external barriers of cold objective structure. Where are the oppressors and their ideology in all this? They seem hidden somewhere behind the Model, and activists are defused having nobody to directly attack.'
>
> (July, 1999:8)

Clearly this is contested ground within the disability movement but the evidence would suggest that if disabled people are not to splinter into smaller interest groups then there is a need for the movement to resist the temptation offered by the reductionism of the social model, without undermining its significance as a macro analysis of the cause of disabled peoples' oppression, and to develop disability discourse so that the differences, as well as the commonalties, of disabled peoples' lives are seen as being equally valuable.

That then is a summary of the theoretical underpinning of the disability movement and contemporary issues which concern it. Both are germane to the issue of education. The social model offers a clear explanation of the socialising role of special education, that is, it prepares disabled people for their second class role in society. Parents are largely absent from discussions because, as mentioned earlier, they are generally seen as having

been innocent victims of socialisation. Consequently, unless parents of disabled children are actively fighting to get their daughter or son into mainstream education, they are sidelined in the debate. That is a challenge the disability movement has thus far eschewed, that is, to endeavour to persuade non-disabled people outside policy making circles that they might wish to align themselves with the aims of the disability rights movement. The absence of such a strategy, problematic and contested though it would undoubtedly be, means that most parents of disabled children are unaware of the level of awareness that disabled adults have of their own disabled identity, and the contribution they could make to raising children and young peoples' awareness. This moves the discussion further towards debates around the recognition of difference, and more clearly introduces notions of separate cultural identities which, in turn, raise the issue of how an education system posited on a mono-cultural model can respond to the needs of different cultures to be recognised and their ideology promulgated. The debate around culture and education will be developed later in the chapter.

It is worth reiterating that there are qualitative difference, between the Disabled Peoples Movement and other inclusionists in that the latter are primarily concerned with education, seeing it as the human right of every child to receive an equal education alongside his or her peers. However, whilst the position of educational theorists, such as Booth (1992), Booth and Ainscow (1998), and Booth et al (1992), might vary in the way it is presented, inasmuch as it tends to focus exclusively on education, this should not be taken to mean that there is no agreement with the civil rights perspective of the disability rights movement as presented by Oliver (1990, 1996), and other writers within the disabled peoples movement. It would be fair to say that there is broad agreement on the issue of civil rights for disabled people, but that educational theorists would see that their effectiveness at pushing forward inclusion is best achieved by maintaining their focus on education policy, practices, and training. The approach of educationalists can be set alongside the disabled peoples' movement which sees education as but one

facet of a society which is constructed in such a way that disabled people are denied their civil rights. However, from both perspectives education is seen as performing a dominant role in developing a 'disabled identity'.

> 'Those of us who live in countries which still support the practice of segregating young disabled people from our non-disabled peers and educating us separately, have long recognised the crucial role this plays in perpetuating our inequality. This practice is a *prerequisite* of segregation later in life, in special colleges, 'training centres', sheltered workshops, residential homes and hostels, separate transport, segregated social activities, and holidays, and the under representation of disabled people in positions of authority or power.' Mason (1992:223)

Here Mason identifies disabled identity in negative terms and refers to the powerlessness of disabled people over many crucial aspects of their lives. One cause of powerlessness has been identified as being the power exerted by professionals. This was also the situation for parents who found that they too were inhibited by the way professionals exercised power in the form of expertise. The discussion which follows illustrates how professionalism can hinder progress.

PROFESSIONALISM AND SPECIAL EDUCATION

Previous chapters have highlighted the significance of the relationship between parents caring for a disabled child and professionals. Particular attention has been drawn to the medical and social work professions, with reference made to education. In this section the focus will be on how professionals in the field of education have developed the notion of expertise in relation to the education of disabled children. This will demonstrate how, firstly, approaches to 'integration' have evolved from existing professional practices, and, secondly, it will be shown how the disabled peoples' movement is critical of professional approaches to educating disabled children, which are seen as reflecting able-bodied attitudes rooted in the

medical model. The two points will further illustrate the difficulties faced by parents choosing a school for their child. From one direction there is the 'voice' of the professional educator who asserts that the child's needs can best be met in a special school. From the other direction comes the body of criticism which says that if a special school is chosen parents will be jeopardising their child's future. Allied to both these views parents have, at best, an ambivalent attitude towards professionals and, at worst, an outright mistrust of their opinions. Clearly then, some understanding of these two elements will add to the accumulating material on parents' choice of special schools.

The 'professionalisation' of learning

Frequent references have hitherto been made regarding the role of professionals in the lives of disabled people. One aspect of these discussions has been the way in which professionals 'create' an area of expertise. The consequence of this is that the holders of that expertise assume a status in their profession and wield influence in the lives of disabled people. Education is no exception to the general rule of professional practice with the teaching of 'handicapped' children being seen as requiring a special qualification over and above that needed for teaching 'normal' children. However, criticisms of education are not limited to a rejection of segregated provision. Also included are rejections of particular approaches which are seen to be associated with the medical model. Such approaches are seen to locate the problem within the individual and, consequently, endeavour to change the behaviour, actions, or attitudes of the disabled person.

An example of the way professional practices can be used to formulate an analysis can be seen in a document produced by the Organisation for Economic Co-operation and Development (OECD). The OECD identified

approaches to integration as falling into three categories: assimilation, accommodation, and adaptation.

> 'Assimilation amounts to refusing to accept that any real difference exists, trying to overlook it or to reduce it by normalising the individual. .....
>
> Accommodation is the stage of integration where the objective is not the suppression of difference, but where the emphasis is on ensuring that the child develops a positive self-image as part of a particular group. .....
>
> Reciprocal adaptation is where the objective is one of reconciling two opposing perceptions that the group should accommodate itself to an individual and that the individual should be assimilated into the group.' (1994:15)

Attempts such as this to identify different practices and then theorise and categorise them, would be seen by the disability movement to do nothing for the rights of disabled people and would serve as a further example of how professionals hijack issues to serve their own ends. Moving on from the example of professional analyses of integrated education, the section will continue with a short exploration of two approaches to 'teaching' disabled people, which serve as examples of how disabled children, and adults, can be singled out by professionals and exposed to programmes of learning.

The disability movement is highly critical of approaches to education which emanate from able bodied theorists and professionals. High on the list of such practices are approaches informed by the theory of normalisation and, to a lesser extent, conductive education.

Normalisation is a concept which first surfaced in Scandinavia in the 1960s but was developed in North America by Wolfensberger. Wolfensberger uses the term 'normalisation, to describe a process by which disadvantaged people can assume a valued role in society. The emphasis on value was taken further by O'Brien who coined the phrase 'social role valorisation' which was felt to better represent the process. Chappell summarises the concept thus:

> 'The normalisation principle argues that people with learning difficulties are devalued by society and have stigmatised identities. A vicious circle of devalued identities reinforced by poor quality services is created. Putting into practice the normalisation principle will transform the vicious circle into a virtuous circle of high quality services which will create high quality lifestyles and enable people with learning difficulties to mix with those who have socially valued identities.' (1997:46)

The issue for disabled people has centred around the notion of 'socially valued identities'. The criticism of Normalisation being that whilst it acknowledges that society devalues disabled peoples' identities, the approach seeks to suppress a disabled identity in the pursuance of assimilated patterns of behaviour. Therefore, by locating the need for change within the individual, it is seen as another development of the medical model.

Social work with disabled people, and further education, particularly in the years succeeding their school attendance, tend to adopt a conceptual framework focused on 'teaching' disabled young adults the skills they are seen as needing to function independently in society. Furthermore, within education in the UK, 'normalisation' and 'integration' are seen as having being broadly similar. That may be so in education (see Booth 1992, Carson 1992) but 'normalisation' has had greater significance on work with people with a learning disability living in the community.

Given that normalisation approaches are laced with references to 'values' the issue for disabled people is 'whose values?' And, on the basis of personal and historical evidence the conclusion would be 'professional values'. They may be wrapped up in phrases such as 'valuing diversity' but at their heart they are classed as able bodied concepts. This further comment from Carson underlines the accuracy of that view:

> 'Normalisation seeks to use valued means by which to offer help. Thus, the help should be given in a valued setting - where others would wish to be; in conducive groupings - among those best suited for learning to occur and in the company of

> others with positive reputations; following purposeful activities in intensively taught programmes of study, and with care taken to remove negative labels/associations, while building positive reputations.' Carson (1992:220)

It is evident from this reference that it is seen as being the role of professionals to, design and deliver programmes, disabled people face having their identity denied if 'normalisors' consider those identities to have 'negative' associations, and what is 'valued' will be based on an able-bodied definition of what is of 'value'.

However, a further interpretation might be that, for example 'valued settings', and 'valued means' would be those valued by the 'de-valued' person and, therefore, they are not determined by able bodied professionals.

This points to something of a conundrum for many disabled people who don't consider themselves to be activists or who, on the whole, may not even be aware of either a disabled peoples' movement, or the politics of disablement. By and large people with impairments want to get on with their lives and will use whatever help is available to enable them to do so. Now that might fit into a professional construct of 'normalisation' but, in effect, it is getting on with what for that person is a normal life. This would be anathema to disability activists who would observe that it is another example of people with impairments being socialised into a false consciousness. Clearly notions of false-consciousness further underline the influence of the social model within the disabled peoples' movement which would, arguably, perceive all professionals as being representatives of the dominant able-bodied ideology.

This point will be returned to later in the chapter when culture is discussed. But to further highlight disabled peoples' critiques of the use they consider able bodied people make of strategies to make disabled people conform to social norms, conductive education will be discussed.

Conductive education has its origins in work done in Budapest at the Peto Institute. It enjoyed popularity, some might say notoriety, as a result of its activities being televised in the UK in the 1980's. Subsequently a number of its practises and approaches were imported and conductive units established in the UK. Conductive education has been criticised for being another example of able-bodied professionals controlling disabled people and manipulating them into conforming to a concept called 'normal'. Read (1998) puts forward the view that conductive education takes a holistic approach by endeavouring to enable a disabled individual to maximise their functional capacity by working with the individual to identify strengths and abilities and, subsequently, to build and develop them.

Nevertheless, although stressing the interactive nature of the method it is still seen as being an able-bodied strategy implemented by able-bodied 'conductors' *sic professionals* and has, therefore, been heavily criticised, most notably by Oliver. Oliver has been unremitting in his castigation of both the approach and its supporters. His criticism is unequivocal:

> 'So, not only is conductive education theoretically unproven but also practically unsubstantiated. I would go further and suggest that it is also ideologically unsound. Its constant, uncritical use of the concept of 'normality' and its insistence on adapting individuals rather than environments flies in the face of much social scientific and educational wisdom, and, more importantly, the expressed wishes of many disabled people who want society to change, not themselves.' (1993:165)

Here, then, we see the twin pillars of the social model, applied to strategies to meet the 'special' needs of disabled children. Namely, (1), strategies invariably require there to be a controlling professional and, (2), also aim to change the individual, not his or her social circumstances and/or environment. In order to further promote change, professionals will often enlist the parents of a disabled child or young person as collaborators. Again parents can find themselves on the horns of a dilemma. They may have been persuaded by, for example, a social worker that if their daughter or son is to attain

independence then they will have to learn the requisite skills by using a particular programme. As already identified, parents may have developed a mistrust of professionals, who have tended to come and go, and may have misgivings about encouraging their daughter or son because, on the basis of past experience, there is a distinct possibility that the worker could leave before the programme is completed. Consequently, parents can be left to carry on providing care, possibly until the next worker comes along and persuades the disabled young person that they need to be moving on. Professionals, then, can be seen as playing a significant role in the destinies of disabled young people, and in the furtherance of that role can potentially be the source of conflict between a disabled young person, convinced of the 'rightness' of the professional's ideas; and her or his parents, who wish to protect their daughter or son from disappointment. So, whilst the disabled peoples' movement is critical of professionals, parents can have their reservations also. Although, as has been demonstrated, parents build up trust with staff at special schools who have demonstrated consistency and continuity over a period of time.

The above section on the professionalisation of learning provides a conclusion to the discussion of issues relating to both inclusive and special education. In relation to the latter, the criticisms are damming. The inclusive movement damns special education for denying human rights to disabled children and the disability movement damns special education for perpetuating the oppression of disabled people, thereby denying them civil liberties.

Is there, then, a case to be made for the continuance of special educational provision? The following section will explore the concept of identity further and consider the notion of 'disability culture'.

A CASE FOR SPECIAL EDUCATION - THE CONCEPT OF CULTURE

Thus far, special education has been presented as achieving two different and contrasting objectives. In earlier chapters it was presented as meeting the needs of parents caring for a disabled child at home. However, this can be seen, in many ways, as a response to the failure of agencies to meet their obligations to families and disabled children. This chapter has developed a theme, articulated in the introduction, which presents special education as a process which socialises disabled children into accepting the status of a second class citizen. A third objective mentioned by the Northern parents and advocated by others, notably Ladd (1988, 1996), is that certain children need specific input which can only be achieved within a specialised setting. Ladd argues that deaf children can only learn British Sign Language to the necessary standard within a specialised setting. Likewise, it would be argued, the level of expertise required to teach blind children mobility skills and to read Braille could not be spread across mainstream schools, there just are not enough children with those needs in one administrative area, therefore, the only logical way of providing high standards of teaching is to locate skills in specialised centres of excellence. Although at a lower level of expertise, the Northern parents identified that they felt that the quality of support their children received in the special school they attended could not be matched in mainstream settings. It is, therefore, difficult to see how there can be any reconciliation between advocates for inclusive education and the parents' belief in the necessity for special schools. Nor, on the basis of the views of disabled people themselves, would it be sustainable to argue for the continued existence of special schools on the grounds that parents value them. Notwithstanding, the next section will endeavour to establish a rationale for a synthesis which suggests that there is a role for special schools.

If a case can be made for the retention of special schools then it is on the basis of two elements. Firstly, that abolitionists are burying their heads in the sand by ignoring the economic realities of the contemporary world. There is no guarantee, nor, in truth, could there be one, that a totally inclusive system would ultimately benefit ***all*** children. Therefore, what is being proposed is a mass experiment in social engineering based on a hypothesis founded on the premise that 'if all children are educated together then they will grow up to be adults without prejudice'. Therefore, as society evolves, bigotry, discrimination, and oppression will disappear. However, this hypothesis ignores, or avoids, the possibility that, should the chimera of inclusion and a society free from prejudice materialise, it could be a society in which educational standards have been so compromised by the all-inclusive paradigm, that levels of knowledge, skills, and understanding fail to achieve the levels required to equip sufficient numbers of people to service the needs of the economy. The second element which would provide sustenance for an argument in favour of a future for special education is the developing concept of disability in a cultural context. The concept of disability as a cultural identity has meant that sub-groups of disabled people have put forward the view that to develop and sustain a cultural identity would be problematic within inclusive systems.

This section will address the above issues by considering, firstly, how work is seen as the achievement which confers success on a disabled person. The problematic nature of this aim is addressed before the second issue is broached. That being, the concept of disability identity and schools as a potential site for promoting disability, and other, cultures.

Education and work

In a consideration of the role of education, Barton and Tomlinson suggest that supporters of integration place their belief for a just and right society in the role served by education in relation to providing 'opportunities for self-fulfilment enjoyed by other people.' (1986:99) However they consider that:

> 'This claim may be part of a misplaced vision, the convictions of which demand closer inspection. It is a romanticism that ignores the inequalities and contradictions that are endemic, not only to special education, but importantly to both the educational system with which further association is being sought and the wider society in which it is located. Too much is being uncritically accepted.' (1984:75)

Written in 1984 it might be assumed that the views expressed therein now lack credibility. Not so, Abberley (1996) cautions against developing a theory of oppression which sees access to the workforce as a goal which will herald a passage to 'Utopia'. The implication being that work is the symbol of liberty and, whilst John (1988) has emphasised the continued significance played by employment, as a measure of status, the nature of work is changing and, therefore, the role of schools in preparing people for work will change also.

The impact of changing work patterns was explored by research into the employment experiences of college students with a learning disability, Tomlinson and Colquhoun put forward the proposition that:

> 'Structural changes in the economy, not a sudden deficiency of skills in the young people, led to the permanent disappearance of much of the work undertaken. This raised questions, never fully debated, as to what kind of education and training should be offered to social groups which were likely to be partially or permanently unemployed.....low attaining leavers from ordinary schools now compete for even those jobs formerly undertaken by those regarded as having special educational needs.' (1995:192)

They conclude that:

'However, in the UK, the signs are that a model of exclusion with the 'special' in their familiar place as a special (unemployable) underclass, defined largely as 'deficient' or 'less-competent' will predominate.' (Ibid:200)

The picture painted is bleak and whilst the social model offers a more than adequate explanation of why it should be so, it does not offer strategies for real-life solutions to how individuals face the problem of seeking work in contemporary society. Nor does it suggest that the adoption of inclusive education would have any impact on employment practices.

A further aspect of the changing nature of employment and, as a result, the nature of vocational training, is the change in the nature of pupils who now attend special schools. Copeland has said that:

'The next step, then, must be the recognition that special education is not a single, unitary idea and that, in fact, there are diverse trends within special education. On the one hand, there is increasing integration into mainstream schools for children with physical or sensory impairments but on the other hand, there is growing segregation for those pupils displaying cognitive disabilities and those with assessed behavioural disorders.' (1993:9)

Caution must be exercised when considering the changed nature of pupils receiving special provision and the significance of terminology should not be underestimated. As Corbett points out:

'All terminology is relative and ephemeral, so that the pupils regarded as 'maladjusted' in that secondary school in the 1960's might well be placed in a special school for pupils with emotional and behavioural difficulties (the elusive EBD's) in the 1990's.' (1997:419)

Even with a generous helping of caution, and scepticism over changes in special education, there is, nevertheless, sufficient evidence to call into question assumptions made about how effective fully inclusive education would be in bringing about change.

A number of references have been made about the unique experience of being disabled which creates a specific identity, that of a disabled person. A development of the concept of disabled identity is a growth in the notion that disabled people can also be seen as belonging to a distinct culture of their own. So, this consideration of an alternative approach to special education puts forward the proposition that it is essential, that the growing theme of culture, as a positive social force, is closely examined.

Dominant references in disability literature to culture have identified it as a negative construct. Culture usually refers to prevailing social mores imposed on disabled people by an able-bodied society. Simon Brissenden believed that disability culture was more than that:

> 'Only people who value themselves, and listen carefully to their own voices have a culture of their own rather than a second-hand culture gifted to them as the price of a silent acquiescence to unthinking 'normality'. (April 1999:36)

This approach to disability culture identifies the need for disabled people themselves to specify what disability culture is and to own it. Notwithstanding, contemporary references to culture highlight the developing concept that disability is a wider collective cultural identity. However, as Vernon (1999), has pointed out, disabled people are not a homogeneous group so any notion that 'disability culture' is universal for all disabled people needs to be challenged. Concepts of culture amongst disabled people have varied dimensions. Firstly there are the feelings of disabled people who also consider themselves to belong to other oppressed groups, for example; disabled women and, more specifically, black disabled women. Comparing society with the disability movement Vernon points to the disability movement as replicating social hierarchies:

> In addition, disabled black and minority ethnic people are an 'other' within the disabled 'other'. As such, it appears that in the disability movement, white society at large is reflected. That is, all the positions of power and influence are held by

white people (the majority) and white culture and white norms dominate it to the exclusion of minority groups.' (1996:258)

Secondly, post-modernist writers have revisited the work of, for instance, Touraine, to look for explanations of social movements in the late twentieth century.

'So, for Touraine, Melucci and Laclau and Mouffe, the social world is cast in terms of its immanence and contingency, seen in its capacity for self-governance and guidance; and social movements as conflictual, particularistic, and activist in the pursuit of their social destiny - what Touraine calls 'society's struggle for historicity.' (Hewitt 1994:203)

As can be seen the latter is conducted in esoteric theoretical sociological language. It is quoted to highlight work done on social movements, of which the disability movement is one. Within that context though, there is scope for other social movements to co-exist, as Vernon has argued. Consequently, the discussion on culture will focus on issues within the disability movement itself rather than on wider issues in society.

The emergence of culture within this context could be seen as a response to the dominance of the social model which:

'developed as it was by British disabled academics and activists, argues that whatever differences or complexities exist in the way people experience disability, the most appropriate research topic is not an individual persons account, but rather their external social environment. The aim is not to understand how people feel, but rather to provide fully inclusive physical environments institutions, policies and practices. Individual accounts are seen as a diversion from the main political struggle of ending collective oppression.' Marks (14,1999:612)

Criticisms of this approach have been voiced by disabled feminists, Crow (1996), Morris (1996); disabled black women, Begum (1997), Vernon (1997), and those who consider it does not offer sufficient scope to accommodate sexuality, Shakespeare (1994).

Notable in debates on the nature of culture and disability have been writers on deafness. Prominent amongst whom is Ladd who argues that for deaf people a collective consciousness and culture is imperative:

> 'Culture as in art is one thing. Culture as in deaf culture is another. Basically deaf people whose first language is BSL [British Sign Language] should be seen as a linguistic minority. It helps if you think of us as parallel to , say, an Asian community. Deaf people have been joyfully getting together since time began, and our schools go back to the 1790's and our clubs to the 1820's. Our language is much older. Deaf people marry each other 90 per cent of the time. 10 per cent have deaf children. Our customs and traditions have been passed down the ages and these, together with our values and beliefs constitute our culture. These parallel other linguistic minorities. The whole definition of culture is so much wider than the one the disability movement is espousing.' cited in Campbell and Oliver (1996:120)

This concept has been developed further by Corker (1998), who has argued that in organisational terms deafness and disability have been defined in relation to work in the hearing and non-disabled environment. Young (1999), refers to a 'cultural-linguistic model of deafness' which identifies the uniqueness of how deaf people experience the world as being one consequence of a shared language:

> ;.....the key distinguishing feature of Deaf people is not that they cannot hear, but that they have their own fully grammatical, natural language (British Sign Language).' (1999:159)

Following Ladd (1988), Young supports the cultural concept that:

> 'Their [deaf people] characteristic traditions, attitudes, values and ways of behaving are now understood to constitute a cultural identity.' (Ibid)

The views expressed above point to a potential ideological clash between deaf people, the disability movement, and proponents of inclusive education. Because, clearly, the consequence of spreading deaf people around the 'ordinary' school system would dilute deaf culture and would, in time, see it disappear with a concomitant diminution in the use of British Sign Language.

This would then lead to the isolation of deaf people. Such 'cultural genocide' Ladd (1988), has argued, needs to be resisted and the concept of culture as a means by which oppressed groups can draw strength needs to be promoted. This argument can be applied to the disability movement which, by adopting a narrow definition of culture can be seen as denying the cultural identity, and significance, of groups of disabled people who have multiple identities. The movement's rigid adherence to full inclusion, particularly in education, can be interpreted as a denial of deaf peoples', and other groups' rights.

This concept of culture has been developed in wider terms by Humphries, who articulates the nature of how cultural identities evolve at community levels:

> 'At the level of the community, groups of people self-defining as disabled or gay, are likely to adorn themselves with the mantle of ethnicity, as they carve out their ways of being, doing and relating, and socialise newcomers into such traditions.' (1999:182)

She does, however, warn that the belief that groups can function with transparency, in a co-existence founded on a symmetry borne of equivalent oppressive encounters with wider society is, 'chimerical, inasmuch as we are all different from each other'. Consequently:

> 'The dream of community can, therefore, become a nightmare for those *bona fide* members of the community who harbour more complex identities, particularly if this is allied to a desire to challenge certain assumptions or traditions.' (Ibid)

Evidence in support of Humphries analysis can be found in the following in which Vernon speaks of:

> 'My need to make sense and consolidate my experience with other disabled Black women was intensified by the fact that there was so little existing literature documenting and analysing our experience.' (1997:160)

What this points to is that people who experience the world in a similar way gain strength from sharing those experiences with each other. Now that can

be denigrated by a rigid adherence to the social model of disability, which would interpret this as being a natural consequence of oppression. Discussions on cultural identity and the need to share experiences exposes the concept of inclusive education as a system which would, inherently, dilute, deny, or dissipate disability as a cultural identity. Ladd (1996), has argued for separate schools for deaf children but the issue is wider than schools alone. It is, therefore, not unrealistic to pose the question: 'Will a person with an impairment feel able to share their experience with an able-bodied person in an all inclusive system?' Even the utopian idyll that beckons from beyond the gates of inclusion cannot hope to remove all the consequences of an impairment. Indeed, research by Priestley (1999), has identified that disabled students in mainstream high schools moved in and out of their disabled identity, to suit circumstances. Whilst their non disabled fellow students recognised, albeit without malice, that they received different treatment from school staff. So, the main themes of the discussion are, firstly, to be disabled is to experience the world in a way that a non-disabled person cannot possibly understand. Secondly, because this experience is shared by many other disabled people in a way that defines them both as an individual and as a member of a group, it can be identified as being a culture, that is, disability culture. Thirdly, care needs to be exercised to avoid homogenising all disabled people so that the shared experience of being disabled does not deny the complex identities that disabled people can have as a consequence of also belonging to other cultural groups. Fourthly, it was argued that disabled people can draw strength from having a shared cultural identity and that this could be promoted within special schools, whereas to distribute disabled children throughout an inclusive system would be to risk denying disability culture, thereby furthering the oppression of disabled children and young people. Having established the concept of disability culture the discussion will move on to consider an approach which could be seen as contesting the notion of collective experience, namely; diversity.

Inclusionists and policy statements on inclusion, offer an alternative to the collective concepts intrinsic to the work of those in support of a strategy based on cultural identity by placing emphasis on 'diversity', and the 'celebration of difference'. Slee believes that:

> 'Inclusive schooling for disabled students embodies the challenge of expressing the full range of human variation in school cultures....' (1997:409)

The OECD sees the inclusion of disabled children in mainstream education as performing a wider task:

> 'What the integrated disabled child contributes is an original and different point of view which is persistently undervalued, but which needs to be understood and respected. This means seeking to understand the child in context and introducing practices that will structure activities in such a way that communication, deliberately placed at the centre of the problem, can fully play its role as a catalyst.' (1994:27)

Corbett offers a rather different slant on the subject of diversity:

> 'I suggested that, whatever the arguments for celebrating the richness and diversity of difference, these could not counteract the reality that certain disabilities were accompanied by significant experiences of physical suffering which impeded quality of life.' (1994:16)

And a cautionary comment on diversity from a disabled person:.

> '....diversity is an overused concept which has become trivialised, and in combination with the pressure for solidarity, has thwarted our self-development.'
>
> Crow (1996:230)

To return to the issue of impairment and the failure of the social model and, consequently, all embracing inclusive policies to deal with the issue of individual needs, precipitated by a impairment. The failure of inclusionists and the disabled peoples' movement, to find an accommodation within its analysis of special education for, pupils who have substantial needs, because of significant and multiple impairments which can require constant personal care and support, indicates a weakness. To ignore the different types of care

that can be needed and to blithely assume that the commitment of policy makers and professionals, and the implementation of inclusive practices will ensure that disabled children will receive the level of care and support that they need, indicates that the ideology of inclusion lacks the subtlety to accommodate 'real' difference. It is possible that 'diversity' has grown out of a need to demonstrate that 'comprehensiveness' has not denied individuality, but Crow's (1996) view that it is an 'overused concept', strikes a truer ring than the assertions of inclusionists, that valuing diversity will solve the difficulties of accommodating different cultural identities within schools designed to meet the needs of the many, and use resources effectively.

However, the idea that students have diversity is not divorced from a concept which has featured prominently in initiatives in several areas of social policy, including education. Consequently it has a bearing on special education and the scope for parents caring for a disabled child to choose their preferred school, is a feature of parental choice. The concept, which is worthy of consideration, is choice and the concomitant notion of consumerism. These contemporary political concepts will feature in the next section.

CHOICE AND CONSUMERISM

Whatever theory is used to explain the existence of special education, and whatever ideology is promoted to either propose its dissolution or support its continued existence; the fact remains that special education is often chosen by parents as their preferred option.

Since the late 1990's rhetoric surrounding public services has increasingly emphasised the notion of the public as consumers. Consumers of health care, consumers of utilities, consumers of council services and so on. This has also applied to education with the Education Reform Act 1988 stressing

the right of parents to choose which school their child should attend. The impact this has had on schools is that they find that they are judged on their position in 'league tables' and, whilst consumerism was very much a part of Conservative policy throughout their period of administration from 1979 to 1997, the concept has been 're-branded' by New Labour who aspire to an ideal of 'citizenship'. However, such concepts can limit the capacity of people to make choice. As Drake argues:

> 'By equating citizens with consumers, their exercise of power is limited to a particular set of predefined choices or even merely to the expression of a preference. Consumerism has little to do with taking control. As in supermarkets, so in society at large, consumers may choose between nicely presented individually wrapped packages of goods and services.' (1999:43)

Drake is highlighting that the notion of choice can be a mechanism by which 'real' choice is restricted. However, it is the rise of such ideological approaches which are gaining dominance in Western societies. One spin off being the rise of groups such as disabled people who are, in turn, invited to participate in the democratic process by being consulted at various institutional levels on policy development. However, one person's 'rights' can be another person's oppression. So it can be seen that if parents are to have the right to choose which school their child attends, based on their best judgement of what is in their child's best interests, and that choice is for their child to attend a special school, then that choice is interpreted as oppressive by disabled activists. This creates a paradox wherein parents of able bodied children can make a choice without fear of being labelled as oppressors, whereas parents of disabled children are castigated for choosing a special school. Clearly it would be naive to imply that all parents are equally able to exercise choice, many factors impinge on that ability. Parents with a higher economic status may choose from both state and private schools, day and boarding schools, without having limitations placed upon that choice because of cost. However, even with the advantage of economic privilege, parents of disabled children are limited in their choice. Whatever the status a school

occupies it is unlikely they are any more inclined towards accepting a pupil with a disability than their state counterparts.

However, Morris identifies that whereas able bodied children attend boarding schools to gain social advantage, this is not the case for disabled children:

> 'When a non-disabled child goes to boarding school it is almost always as a result of parental choice and the ability to purchase what they believe to be a better education than is available to them in local state or private schools. This is also one reason why some parents ask their local education authority to pay for their disabled child to go to boarding school.
>
> However, while for non-disabled children being sent away to boarding school is an expression of advantage and privilege, for disabled children it is more likely to be associated with disadvantage and exclusion. Even when parents of disabled children feel that they will get a better education by going to boarding school, sending their child away is not something they freely choose.' (1998:77)

Rather, for parents of a disabled child, 'boarding school' is seldom a choice. As Abbott et al (2000) found; if a disabled child does attend a residential school, it is more likely to be because the local authority has been unable to meet the child's educational needs locally and/or because of pressure on families caring for a disabled child at home. Further evidence for this is provided by Gordon et al (2000), who established that there was a disproportionate number of children with complex disabilities between the ages of 11 and 15, in residential settings, when compared with non disabled children. Thereby indicating that parents finding it difficult to support their disabled child at home have little choice but to allow their child to go into residential care.

It would appear, therefore, that choice for parents of disabled children is not as wide as that for parents of able bodied children. Nevertheless, limited though it may be, it still allows parents to exercise some element of choice in the location of their child's education. If special provision, and special

schools, were to be abolished in favour of a fully inclusive system, as proposed by both the inclusionists and the disability movement, then a consequence would be a reduction in the options currently available to parents of a disabled child. The question could legitimately be posed: 'Is this not also a denial of parents' civil liberties?' If on the one hand, the state is to make parents responsible for their child's attendance at school, and their behaviour outside it, it is difficult to square the circle if they are not also to be trusted to make a judgement on which school their child should attend.

SUMMARY

The introduction to this chapter gave the view that if sense was to be made of the choice by parents to send their disabled child to a special school, then it was necessary to have a grasp of the political, cultural, and theoretical elements which form the arena within which debates on special education take place. Consequently, special education needs to be viewed within a political context which has complexities reaching beyond a simple polarisation of views which see education as needing to become wholly inclusive, or maintain the capacity for disabled children to be educated at special schools. It has been shown that the lobby for inclusive education has three primary supporters. Namely; professional educators, who see inclusive education as a human right; parents' groups, who believe that inclusive education should not be denied to them if they choose it as an option for their disabled child, and the disability rights movement; which sees inclusion as one element in the quest for civil rights for disabled people. It has also been shown that within groups which adhere to the quest for inclusive education there are differences which further complicate efforts to articulate and analyse the debate which inclusion has become.

It was argued that education cannot be separated from other elements in the life of a disabled person because the process by which a disabled person is educated plays a significant part in shaping their identity. However, disabled people and the disabled peoples' movement argue that the identity disabled people leave special schools with, is a negative one. Inclusive education is, therefore, seen by many as the means by which disabled young people will acquire a positive sense of their own identity, it will also provide a solution to the oppression of disabled people, and provide one route by which they will achieve emancipation. However, the view that culture is a vital element if oppressed groups are to gain the strength to tackle oppressive practices, was proposed. From this stance it was proposed that individuals have complex identities so the disability rights movement needs to find an ideological approach, a synthesis, which embraces the variation in its membership. Such an approach needs to acknowledge that race, sexuality, impairment, and gender, also impact on individual disabled people. The point being that to be disabled does not necessarily mean that that is the identity a person wants to have, and that disabled people may also have other identities which they value and do not wish to be submerged. The concept of disability culture was developed and it was suggested that culture may offer a more flexible and relevant way of interpreting the complexities of identity which the reductionism of the social model, some feel, fails to do. Disability culture, it was argued, offers a rationale for special schools because the homogenisation resulting from inclusion in a comprehensive system, designed to cater to the abilities of the many and meet the needs of society, would probably extinguish disability as either a valued individual identity, or as a shared cultural experience. The argument was further developed to suggest that special schools could be a site for promoting disability culture in a positive and constructive way, and that this is a legitimate rationale for the continuance of special schools whereas, strong though the reasons are, a rationale based on the needs of parents of disabled children alone would be unsustainable. It also needs highlighting that special schools operating within a paradigm of disability as a cultural identity is no less likely to deny other cultures than are mainstream schools,

unless stringent practices based on the notion of culture are followed. That said, it would be easier to follow positive practices if the conceptual framework of the school emanates from valuing cultural identity because if that is the ethos then it is a shorter step to other cultures than is the stride from homogenous education to culture. Nevertheless, the challenge is clear and will be developed in the concluding chapter.

The chapter was completed by a discussion of consumerism and posited that consumerism and citizenship can be implemented in such a way as to limit choice, thereby negating notions of consumerism and put into question citizenship as an ideological approach aimed at achieving equality and, therefore, a fully inclusive society. The concept of choice was considered in relation to parents and their ability to choose a school for their child. The view was propounded that if parents are to have choice then a consequence of that choice might be the choice of a special school. Therefore, if special schools are abolished in the pursuit of inclusion then parents are being denied a choice in deference to a conceptualisation of citizenship which places homogeneity above individuality.

This chapter forms the final part of the discussion establishing the contextual framework of the study. Chapter 6 will draw together the converging themes relating to parents' choice of special education and consider how the needs of parents caring for a disabled child and the need for disabled young people to leave school with a positive self identity can be meshed with the ideological position of the disabled peoples movement, and challenge the view of inclusionists who argue that special schools must be abolished, and a inclusive system of education introduced.

Chapter 6

Conclusion: Making Sense of the Choice and a Way Forward

INTRODUCTION

The introduction to this thesis described the process it was to document as 'a journey'. The journey was one which had commenced with the belief that, in my judgement, special education for disabled children was, failing to equip disabled young people with the skills and self identity to assume full citizenship alongside their non-disabled peers. At that initial stage it was strongly believed that parents of disabled children bore a level of responsibility for colluding with the oppression of their disabled children, by continuing to choose special schools. Attention was also drawn to the argument that parents were aided and abetted in the choice by education and caring professionals who were considered to manipulate or coerce parents into choosing special schools. The objective, therefore, was to find out what did, in fact, influence parents in their choice, and to establish precisely why parents of disabled children choose special schools.

Charting the journey took the route of, in the earlier chapters, considering research conducted with a group of twenty four parents, referred to as the Northern parents. The documentation of their experiences of caring for a child with an impairment were considered in relation to their child's attendance at a special school. The Northern parents revealed that the different facets of their lives interlink and overlap to form a complex network

of services and support mechanisms which enable them to support and care for their disabled child.

Chapter 4 then went on to place the experiences of the Northern parents within a wider context by considering how the specific experiences of the Northern parents compared with those documented in research and literature concerned with similar issues. It was stated that the thrust of the research had been influenced by the responses parents had made in the initial survey questionnaires. Consequently, to facilitate the acquisition of information on a range of aspects concerning parents' experiences of caring, it was decided to avoid the potential dangers of adopting a narrow focus which concentrated solely on special education. The danger of such a narrow focus, it was felt, would be that parents' capacity to articulate their experiences of caring for their disabled child would be inhibited. Accordingly, Chapter 4 analysed the issues raised by parents, alongside a wide range of existing research and literature so that comparisons and contradictions could be located. So it was, that a number of similarities were identified, as were differences. However, it would be fair to say, such were the similarities between the Northern parents and the experiences of other parents caring for a disabled child, that the Northern parents are not untypical and can, therefore, be interpreted as representative of the generality of parents caring for a disabled child. Chapters 2, 3 and 4 formed the substantive empirical work, whilst Chapter 5 went on to provide a critical consideration of social and political factors germane to the issue of special education and parental choice. The significance of those factors was stressed, because those factors have produced the theoretical and ideological framework within which the Northern parents' choice of a special school must be considered, and, understood.

Building on the need to articulate the political and ideological background within which special education rests, Chapter 5 explored the complexities associated with discussions of special education and disability. Those complexities were examined in relation to, firstly, the debate on inclusive

education, secondly, the politics of disablement, thirdly, the concept of disability as a cultural identity and, finally, the notion of choice and consumerism.

Taken separately the above issues each have a sense of their own, and whilst that may be contested, it is evident. However, what is less evident is how the sum of the parts contribute to a holistic understanding of parenting a disabled child and, in response to the aim of the study, their relevance to why parents choose special schools for their disabled children. The aim of this chapter is to make sense of that choice by locating the rationale for that choice, within the context of the myriad factors impinging on their lives.

The chapter will, firstly, summarise what are considered to be the main issues arising from the research and the examination of allied elements. Although several issues will emerge the chapter will go on to identify the predominant factors which both offer an explanation for the choice of special education and propose a radical way in which special education could make a positive contribution to the development of disability culture, and provide the location for directing support systems.

EMERGENT ISSUES

Unravelling the complexities surrounding the choice of special education and its continued existence needs to be approached in a measured way if a sense of why that choice is made is to bear scrutiny. Initially, therefore, the issues arising in earlier chapters will be considered within specific spheres before being merged to form a coherent whole. In the first instance, issues arising within the sphere of the home, that is, those issues concerned with the care of a disabled child, will be identified. The focus will then move on to issues

pertaining to the sphere of education before completing the section with issues resulting from discussions on the political context of disability.

Issues within the home

The results of the research conducted with the Northern parents demonstrated that there is a distinct gender differential in the care of disabled children. Mothers provide the majority of personal care, attend routine hospital appointments, link with school, and are generally available 'on call' to service the needs of their disabled son or daughter. As a consequence mothers do not pursue personal objectives in terms of work, career, or social activities. Furthermore, mothers felt that as a consequence of meeting the needs of their disabled child they spent less time with their able bodied children than they felt either they should, or would, if it were not for caring for their disabled child. Not only was this felt to impact on time spent with their other children in the home, but also on the capacity to take part in social and leisure activities as a family.

Mothers spoke of feeling 'isolated' and 'apart' from their peers and that they considered that their responsibility towards their disabled child was different to, and went beyond, that expected of them in relation to their non-disabled children. This resulted in parents, particularly mothers, feeling that they would care for their disabled child into adulthood and that this extended care was an implied expectation, both by society in general, and on the part of health and care agencies in particular.

With few exceptions parents received little or no support from social services departments within the home. Furthermore, most parents had no contact with their social services departments. Although, parents of older children identified social services as becoming involved when the annual review of

their child's special educational needs was held at the time of the fourteenth birthday.

Parents identified the support received from staff at their child's special school, and the links developed with parents of other disabled children, as being a key source of support and information. Information was highlighted as an important need as a means of allaying anxiety. Anxiety levels were said to be at their highest at 'key stages' in the lives of their disabled children, with particular emphasis placed on transition points as periods of high anxiety. The lack of information provided by statutory agencies regarding services and options for the future was cited as being part of a larger picture in which professionals had come to be seen as being reluctant to offer advice, information, or make decisions which had resource implications, Consequently, the pervading ethos was that professionals had to be confronted and challenged in order to obtain a suitable service and unlock necessary resources. Parents, therefore, defined their relationships with agencies in terms of a 'struggle' or 'battle', so that a basic mistrust of the medical, and other professions, prevailed.

One outcome of the largely negative relationship with service providers was that parents were mostly, at best, uneasy about how service providers could support their disabled child when they became adults and could, potentially, move out of the family home. At worst parents just did not believe that service providers would provide the level of care and protection that would be needed if their daughter or son were to be enabled to live in a home of their own. And whilst parents saw this extended care as being a reasonable extension of their parental role there were concerns about what would happen in the long term when they could no longer provide the care themselves. Whilst the latter point takes the discussion into an area beyond education and school attendance, it is important that the issue is made known because it is a growing concern for parents as their disabled child approaches

the transition from school to post-school, and graduate to adult services, rather than provision designed to meet the needs of children.

Health and personal relationships were seen to have been affected by the above factors, which were shown to contribute to high stress levels in families, and between parents and partners. Indeed, the requirement for some form of service which could respond to what parents felt was a need for emotional support, was identified by parents as being necessary. This, parents felt, did not need to be an elaborate counselling service but rather some form of 'safety-valve' which could be used to relieve extremes of stress, whenever these occurred, and at whatever time of day they arose. A specific period when emotional support would have been valued was at the point when it was disclosed that a child had an impairment. Whether this was at the time of birth, or later, did not matter. It was the event itself which was defined as being highly emotionally distressing. Again, at this time, mothers felt that they often had to carry the emotional load as fathers tended to find the news harder to deal with. Or, at least mothers felt the need to support the child's father, which is not to say that mothers felt any *less distressed*, *but* rather that they felt they should try and 'be strong'.

THE ISSUES

Looking at the results of the research and the literature as a whole, the emergent issues can be defined within a number of categories. The first category being the impact of caring for a disabled child on mothers. It was found that, mothers are the main providers and source of personal care, mothers have few opportunities to pursue an active life outside the home, and, mothers often bear the emotional strain identified as being a consequence of caring for a disabled child. The second category was support from statutory agencies. The findings were that social services

departments offer little support to families caring for a child with an impairment, and there is a lack of information on services provided for parents. As a result of these experiences, parents worry about the ability of services to provide for the needs of their disabled daughter or son and consider that they are the best, if not only, people to advocate on behalf of their daughter or son's needs. In addition parents have an ambivalent relationship with medical and care professionals and feel ill served by statutory support services.

Many of the stresses experienced by the Northern parents were ameliorated by support received from staff at the three Acorn Society special schools. But the inability of statutory services to offer guarantees about meeting support needs beyond school, create a void which parents fill with anxiety and their commitment to continue to provide care.

Although special schools do have a significant role in the lives of those parents whose child attends one, there are clearly areas that are not covered. A reason for this is that although special schools provide a range of medical and para-medical services on site, which means that mothers do not have the responsibility of organising them, they are obliged to operate within a curriculum. Consequently, special schools, like their mainstream counterparts, are managed and regulated within an education system. So, despite the presence of ancillary support, the support parents get from staff is still largely confined to school time frames, that is school days, school terms, and statutory ages for school attendance.

Clearly then, whilst special schools provide a valued source of support, their role goes no further. Although, taken overall, the time a child spends at school is limited, the influence on social development is immense. It is at school that children interact with others from varied backgrounds, different cultures, and with differing abilities and ages. These are the factors which are said to be the problem with special schools. Special schools are said to deny

their pupils the opportunity to have those experiences and, therefore, children who attend special schools grow up without the social skills or self belief to assume a role amongst their peers in adulthood. These issues were explored in Chapter 5 and the emergent issues in those discussion form the basis for the continued discussion.

EMERGENT ISSUES IN INCLUSIVE AND SPECIAL EDUCATION

The Northern parents had responded to the issue of inclusive education pragmatically. With few exceptions parents believed that the ideal for their child would have been for them to have received their education at a mainstream school. However, in a number of instances, usually for children with severe and multiple impairments, special schools had seemed the only option. That is not to say that they had not considered alternatives but, for these parents there had been an assumption from a very early age that their child's needs could only be met within a special environment. It tended to be those parents who saw the practical value of the provision of para-medical and other services on a centralised site. On the basis of arguments put forward by disabled ex-students of special schools, and disabled activists, those parents could be seen to have been socialised into this mode of thought by professionals involved with them in the early years of their child's life. A number of these parents identified Child Development Units (CDU's) as their earliest source of involvement with professionals, and the time when they and their child attended the CDU, as the time when future directions were discussed. Often this was where and when it was made clear that their child would need to receive special provision if their needs were to be met. Those parents tended to absorb this information and took it for granted that this would be the case throughout their child's school years. Although these parents could be said to have acquiesced unprotestingly to professional

views, this would be to assume that they were unable to separate their child's needs from professional guidance or, indeed, their own needs. Nor would it credit those parents with having debated alternatives, or continued to consider what was best, before concluding that there was no realistic way in which their child's needs could be met in a mainstream school.

The situation for parents whose children had speech and communication disorders was substantively different to that of the parents discussed above. For those parents the decision to send their child to a special school had been the result of rational, measured consideration. This was usually based on having found that mainstream schools did not meet their child's needs, but they too had concluded that the particular special school they had chosen was, in most instances, the only one within a reasonable geographic area which met their child's needs. On the evidence presented it would be unworthy and disingenuous to dismiss parents' choice of a special school as the 'easy option', with the implication that they were passive victims of a process designed to delude parents of disabled children.

Of course it could be argued that this is further evidence that inclusion is not actively promoted by education authorities and that parents will, therefore, take the line of least resistance and opt for special provision. But, given the level of care required by their child during the long periods out of school, it is hard to be judgmental when other services fail to offer any degree of support. If special schools are virtually the sole source of support parents receive, then, in the absence of any alternative, whether that be as a consequence of the offer of mainstream education or a package of support which would enable them to pursue a place at a mainstream school, then to decide against a special school would, in their eyes, have consequences both for the education, and beyond, of their daughter or son. This is because if, as indicated above, mothers are the primary care providers, and also bear the brunt of emotional demands within the family, then there is scant evidence to indicate that if their child attended a mainstream school, then the level of care

and the emotional demands on mothers would not face significant increases. It could, therefore, be argued that to adopt inclusive policies without increasing levels of support would be to follow the path trodden by successive social policy initiatives, such as community care, which has seen the policy of 'care in the community' become referred to as 'care by the community'. That is, to reinforce gender stereotypical activities by creating the circumstances in which womens' caring roles would be a requirement for those policies to have the veneer of effectiveness. Inclusion, by this analysis, could be seen as a middle class ideal espousing notions of human rights and citizenship for disabled children, whilst concurrently denying the same rights to mothers of disabled children. Because, as was evidenced in Chapter 4, it costs three times as much to bring up a disabled child as it does a non-disabled child, poorer parents will face greater difficulties than their better off 'middle-class' counterparts and are less likely to push for a policy which further limits their scope to earn additional income. Parents from higher socio-economic groupings are more likely to have incomes which enable them to commit themselves to ideological causes, because they have the capacity to purchase private care, and do not have the same necessity to seek extra income in those areas of employment which can accommodate the availability of mothers caring for a disabled child. Unfortunately, there is a danger that this greatly over simplifies the role class plays in the debate. Furthermore, because the issue of class was outside the parameters of the research, it is conjecture rather than supportable hypothesis. But, nevertheless, there is sufficient implicit material to give pause for thought.

That, however, whilst identifying the issue of care as a gender issue does not cover the spectrum of reasons behind parental choice of special schools. A further rationale provided by the Northern parents for their child's continuing attendance at a special school was that they considered this to be the only environment in which their child could receive the expert tuition and therapy they needed. Many of the parents in this category had similar demands on their time to those of parents discussed above, but children whose parents

had actively chosen special provision and then located the school which they felt met their child's needs predominantly, had what are defined as 'speech and behaviour disorders'. These tend to be absorbed under the umbrella descriptor: 'autism'.

These parents differed from those discussed above because their experiences were of having to battle to get their child's educational needs acknowledged, and having to struggle to get her/him into the special school of their choice. Although they were frequently offered guidance by professionals, that there was a particular unit or school which could provide for their child's needs, they then had to convince local education department officials that their choice was best for their child. The issue of mainstream education for these parents was of having had to take their child out of mainstream school because they were falling far below what parents believed was an appropriate standard, or because teaching staff had refused to teach their child because of her/his behaviour towards other children at the school. In a number of instances parents had visited units within mainstream schools, but felt that they did not provide either inclusion or the quality of teaching required. Usually, it was said, because classes contained a wide range of children with different impairments so, consequently, none of the children had their individual needs met. This was often seen to be the worst of both worlds, exclusion masquerading as integration, and poor teaching.

In the case of these parents it could be argued that if sufficient, and appropriate, support and teaching, were provided then they would not have been in the situation whereby they had to make a choice. Furthermore, it can be seen as being in the vested interest of teaching professionals to create need in order to promote their own careers. That is, on the one hand there are teachers who argue that they neither have the skills, nor resources, to cope with pupils with different educational requirements. On the other hand there are teachers who have had special training who then become 'specialists' who receive a premium payment for teaching 'special' children.

Whilst it is self evident that in order to resolve this situation all teachers must be trained to teach all children, there is little to indicate that this is a part of future policy. Indeed, it could be argued that with the shift from the university campus to the school classroom, as the primary location where teachers qualify, there is more likelihood that trainee teachers will assimilate current practices, rather than develop new skills and attitudes. Strategies to support children with 'special needs' in mainstream schools, invariably depend on extra support for teachers. Whilst, in some instances, this may meet the needs of the disabled child in the classroom it is highly debatable that it would resolve the difficulties disabled children have faced, and do face, in the wider school environment.

The size of comprehensive schools was often cited as being a reason why a disabled daughter or son would be unable to cope in the mainstream, and whilst this too could be described as protectiveness on the part of parents, it does raise one of the premises on which the inclusive project is founded. That is, that by including all children in a comprehensive all-inclusive system of education, differences would no longer be seen negatively but would be accepted as merely being part of the varied mixture of people who comprise humanity. Therefore, as successive generations of students moved on into the world so they would take with them the values borne of receiving their education within a non-judgemental environment alongside their peers, both non-disabled and disabled.

Certainly the logic of this view can be seen from sociological theorising which, from within certain perspectives, would point to inequalities as being the product of structural social practices. Consequently, if the structure that produced those inequalities were to be altered then the cause of the inequalities would disappear. Such a task requires an ideological commitment of the deepest faith. Given the inherent inequalities in British society, which are manifestly mirrored in education, it takes an enormous leap of faith to assume that by compelling all children within the state education

system to be educated alongside one another the prejudices felt towards disabled people would be eradicated over time. Furthermore, this is expected of a society which continues to permit people with sufficient financial resources to 'buy out' of the state education system. Not only can some parents buy out, but schools which are maintained by religious faiths have been allowed to co-exist for many years. And, moreover, as long as education attainment is seen to be being met, then parents can educate their children at home. It, therefore, seems paradoxical that if these variations to the system are to be accommodated, then to insist that special schools for disabled children be abolished is to single disabled children out and deny their parents an equivalence of the choices other parents enjoy, on the grounds of faith, or wealth. Of course, if parents of disabled children have the necessary resources then they too can 'buy out' of the system.

It can hardly be a surprise that the Northern parents chose special schools rather that expose their children to inadequate levels of support, inappropriate teaching, and potential isolation. Additionally, such a choice would be accompanied by increased demands on mothers for support and care.

So, it can be seen, that for the Northern parents, at least, inclusion risks ignoring wider social aspects and the product of adopting a view based on educational factors alone would be a distinct probability that there would be an increase in the exacerbating factors highlighted above. However, nor can the wider aspect of a child's life and development be restricted to the home alone. The next section will, therefore, go on to consider wider social issues, which arose during earlier discussions, in relation to disability rights, and the concept of disability as a cultural identity.

DISABILITY AND IDENTITY: EMERGENT ISSUES

Hitherto, the discussion in this concluding chapter has identified ways in which the abolition of special schools would impact on parents, in particular mothers. Such a conclusion would point to there being a conflict of interest between the needs of parents who care for a disabled child, and the effect attending a special school is said to have on the socialisation of a disabled person. The latter, it has been argued, results in a disabled person acquiring a negative self image and also failing to develop the skills necessary to function in society or to be enabled to take a part in the country's economic production. The evidence presented to support this point of view is convincing and congruent with the social model of disability. However, this view has a number of inherent assumptions. Firstly, there is a lack of recognition that differences exist between, and amongst, disabled people. The social model glosses over difference and views disabled people as a homogeneous whole. Secondly, culture is ignored. And, as was argued in Chapter 5, disability as a cultural identity has growing support and, whilst acknowledging the risks of ignoring other cultural identities, offers a coherent basis on which to develop the idea that disabled children can gain strength and a genuine sense of pride in their own identity from promoting the idea that being disabled is special, not in the pejorative sense that the word 'special' currently denotes in education, but in the sense that to be disabled is to experience the world in a unique and special way. So, simply put, by ignoring the cultural aspect of disability, inclusion stands accused of being little more than a euphemism for normalisation. Because, without the recognition of disability as a cultural identity and the scope to develop that identity within a mainstream school system, there is the distinct possibility that the dominant culture of the majority will subsume those of the minority. The deaf community argued that this would be the situation if deaf children were included into mainstream schools because they would not learn to use British Sign Language and, therefore, not acquire the ability to communicate, or share experiences with, other deaf children. The only way deaf culture can be sustained, the argument states, is by the continuance of special schools for deaf children in which they can learn BSL and deaf culture can be allowed

to flourish. The disabled peoples' movement have accepted this argument but it is treated almost as a 'special case' and has not caused any revisions in the overall application of an inclusionist approach. A view very much in keeping with the structural foundation of the social model of disability which provides the basis for the critique of special schools mounted by the disability rights movement. This exposes weaknesses intrinsic in structural approaches, highlighted in Chapter 5, in that they can be seen to provide coherent explanations at a macro level, in this instance the social position of disabled people as a collective whole, yet there is a failure to provide solutions to difficulties experienced at a micro level, in this instance, how minority cultures can be promoted within a national education system designed to serve a dominant ideology founded on the need of the nation to be economically productive.

The issue of difference is problematic because disabled people have struggled to shake off the medicalisation of impairment, largely by proposing that the social model provides the true definition of disability. It is clear that, for reasons of unity, in the face of a hostile and oppressive society, individual limitations in capacity need to be conflated into an argument designed to establish civil rights for disabled people. However, this does not remove the fact that some children have impairments which are of such a complex and substantial nature that the extent of their impairments make it unrealistic to assume that they can either perform an economically productive role, or reach the cognitive level necessary to enable them to control their own lives. This is not to suggest that individuals fitting this description cannot influence how their lives are managed and that strategies and practices should not be employed to ensure that wishes are acted upon, but rather to suggest that it is ideological hegemony to ignore the significance those differences have for the individual. It is difficult to see how children with complex and substantial degrees of impairment would participate if they were included in mainstream schools. Schools, that is, whose curriculum is increasingly concentrated upon academic achievement and 'key stages'. A curriculum which is driven by the

demands of commerce and industry to produce a more numerate and literate workforce. The argument can become circular as it is argued that that in itself is no reason to segregate someone from their peers and that, regardless of their future role in the economy, all children should be together. This massing of all children leads on to further discussion of the second issue, namely, cultural identity.

It has been argued that disability is a cultural identity and should be recognised as such. However, the argument was presented in earlier chapters that whilst a person may possess a disabled identity and, therefore belong to a disability culture, an individual may also possess other identities. Race, gender, and sexuality were highlighted as being identities which may be subsumed under the mantle of disability. Accordingly, if mainstream schools have so far been singularly unsuccessful in developing multi-cultural approaches and maintaining anti-oppressive policies it is difficult to see how a disabled child would develop any notion of identity other than to see themselves as different. The inability of a comprehensive national education system to accommodate religious differences has been recognised, so it is permitted for special schools to operate based on a particular religious faith, providing the requirements of the National Curriculum are met. If one follows the line that it is necessary that disabled children are enabled to develop an identity rooted in the concept of disability culture, then it is not too far a leap to suggest that special schools for disabled children should also be permitted to operate on similar lines. That is one of the difficulties with the argument for inclusion. If it is acceptable for one section of society to run schools to meet particular ideological needs, it is clearly problematic to deny another section of society the same right.

Therein lies a key issue for both education policy, inclusionists, and the disability movement. A conclusion needs to be arrived at as to whether disability is definable as a culture. The deaf community have argued that they have a cultural identity and because they share a common language they

fulfil the definition of an ethnic group. However, this has not yet been acknowledged by government, which throws into relief the difficulty British society has in coming to terms with multi-culturism. The concept that disability should be acknowledged as a culture challenges a society which tends to define itself as pluralistic rather than cultural, and whilst the concept of societies organised around people associated through shared interests can be seen to follow a twentieth century sociological theme, the concept of a society organised around cultural identities tends to challenge pluralism. Consequently, if special schools were to be validated for cultural reasons then the ramifications would be far wider than in the provision of education alone.

The emergent issues have been articulated and efforts made to identify the debates surrounding them which make for the complexity of the overall debate. The subject of a future role for special education will feature in the next section. However, before moving on to consider that role, it would be useful to reflect on the key issues to emerge thus far. These will be summarised in general terms, more as a means of sharpening the focus on the key issues so that the discussion has a solidly constructed platform for the subsequent discussion.

It has been established that the main issues in relation to inclusive education and the disability rights movement were that, special schools were responsible for socialising disabled children and young people into seeing themselves as being dependent and not having a valuable adult role to play, parents were seen as being guilty of helping to perpetuate special education, either by omission or commission. and policies should be enforced to ensure that all children are educated in an inclusive setting.

To set against this position the consequences for disabled children of being included in a mainstream school were broadly seen as the risk of being denied the opportunity to develop a positive identity through promoting the cultural concept of disability, Furthermore, it was suggested that disabled

children with complex and substantial impairments faced the possibility of being isolated within mainstream schools thereby being more isolated than if they were in a special school.

SPECIAL EDUCATION - A FUTURE ROLE?

The situation is clear; the Northern parents were committed to the role and function of special schools. For them, they provide the support absent from other sources and the security of knowing that their child is in a safe and caring environment. Inclusionists are equally clear about the role and function of special schools; they provide the means by which disabled people acquire a negative identity and the expectation that they will occupy a second class role in society. The disability movement sees special schools as one means by which disabled people are maintained in an oppressed position in society by the reproduction of a dominant disablist ideology.

Each of these conclusions is equally valid so, if special schools continue in their present form, inclusionists will see oppression and the denial of human rights perpetuated. Conversely, if special schools are abolished then parents will face increased levels of care with mothers continuing to be isolated and with increased levels of care and responsibility. Although the two positions appear to be clear the overall situation is muddied by a lack of clarity on the part of research into inclusive strategies. Sebba and Sachdev (1999), reviewed a range of inclusive education projects and found wide variations in their effectiveness. Indeed, one of their conclusions was that it was highly problematic to draw conclusions because no two inclusive projects were the same. What was apparent from Sebba and Sachdev's review was that there does not appear to be a uniform definition of inclusion and, whilst they offer one in their text, there are problems when it is applied to educational practices. An example of this can be seen in the London Borough of

Newham. Newham has a policy of closing all its special schools and had reduced them from eight to two by 1996, with the expectation that by 1999 all pupils would be included in the mainstream, with the remaining two schools closed. However, when one examines the way Newham operates it does not have the feel of full inclusion, nor does it indicate that parents would have choice. This is because children with moderate learning disabilities are generally accommodated in their local comprehensive whilst those who need regular therapeutic input are located in 'resourced' schools. Consequently, it may be assumed, if a child fits that category then she or he will be obliged to attend the 'resourced' school where the therapy is concentrated. So, it can be seen that resources are still determining policy and disabled children can still expect to be transported out of their local neighbourhood to be educated.

That is one aspect presented by the spectre of inclusion which has prompted Sutton (2000:31/32), to comment on the 'orthodoxy' of inclusion which, he believes, has led to the stagnation of special education over the last twenty years. Sutton challenges inclusion and advocates the regeneration of special education by adopting a system of '*cognitive education*'. This approach is part of a concept Sutton refers to as 'dynamic inclusion' which incorporates the notion that children should be educated in the environment which is best suited to enabling them to learn. The underpinning philosophy of dynamic inclusion being that education can transform an individual and that education should not merely be about educating every child, but should be aimed at educating every child 'well'. The rhetoric of inclusion, Sutton believes, will not achieve this, but will merely serve to polarise those who adhere to the inclusive ideal and those who want choice. The positions appear to be irrenconcilable, on the one hand inclusionists argue for a total move towards inclusion whilst there are those who continue to advocate the need for special schools. It is evident that there is a need for an alternative approach which meets the needs of disabled children, and their parents, and does not perpetuate a system which dis-empowers disabled people. The evidence provided by Sebba and Sachdev (1999), suggests that there is a long way to

go before inclusive education can be anything other than integration by default, as the case in Newham demonstrates, or a disparate collection of differentiated projects offering suggestions on what is useful to enable inclusion to work, most of these being 'pilots' or small scale projects. Equally, if caution needs to be exercised in the area of inclusion then the views of Sutton (2000), need to be treated with caution also. Sutton advocates a particular approach to special education, not a new one he freely admits, which will, one assumes, be directed by professional educators. True the cognitive education approach requires the close and active involvement of parents, but it returns us to the issue of the relationship between parents and professionals, discussed in Chapter 4, and whilst this approach may indeed offer a way to maximise the learning capacity of disabled children, it depends on many variables with power located in the hands of, one can conclude, non-disabled educationalists.

What is also evident is that neither approach adequately addresses the issue of family support. Sebba and Sachdev (1999), identified one inclusive project in which a multi-disciplinary approach had been adopted so that support was provided in the school, and in the home. The team included a social worker, care assistants, therapists, nurses, and school staff, both teaching and support. This project reinforced the conclusions reached earlier, namely that if inclusion is to work then it needs collaboration between different agencies and a high degree of resourcing. But, as often stated, such a degree of resourcing does not appear to be readily available. Equally, the evidence points to a lack of involvement on the part of social services departments in the years leading up to a disabled child leaving secondary school. Therefore, there needs to be a shift in the mind set of social services departments so that they recognise that involvement in the life of a disabled child will be a lifelong connection. This is a contradiction in contemporary social work practice which is, to a large extent, concentrated on assessing need, planning a package of care, and then sub-contracting the provision of that care. Social workers need to be more closely involved with families caring for a disabled

child, but this, and the issues above, beg the question as to how, and where, this could be delivered. The next section will propose a radical and creative way in which the disparate elements, which have hitherto seemed irrenconcilable, can be resolved to provide a system of education for disabled people which offers a route from the present situation, to a future in which disabled children could be equipped to assume an adult role in society.

A WAY FORWARD?

The previous section summarised the different viewpoints on special education and, given the discussions which have taken place in earlier chapters, the unsurprising conclusion was that views on the future of special education are split. Bluntly put, there is a split between those who would completely abolish special schools for disabled children, and those who believe that there is a continuing need for special schools. However, as mentioned earlier, the debate has largely been driven by the dominance of the 'rhetoric of inclusion' so that supporters of the continuance of special schools have had to struggle against policies and a shifting paradigm to make their case. If, on the other hand, one approaches the debate from a different angle and view the future of special schools from within a perspective which asks the question: **'How could special schools operate so that disabled children were not disadvantaged and parents were supported?'**

Taking that question as its starting point this section will present an exploration of a future which offers the proposal, that special education can have a place in a diverse education system, focused on meeting different needs. Clearly, this will require an ideological shift from a blanket inclusionist approach to an acknowledgement that inclusion cannot benefit all children in the way the rhetoric asserts. The proposal which follows is premised on the belief that disability is a cultural identity and that if this is accepted then it provides a prism through which special education takes on a different hue.

The contested nature of this concept is acknowledged but, if the concept is taken as given, then a case can be made for educating disabled children collectively.

It is a fact that within the education system special schools exist. Granted, there are critiques founded on ideologically based opposition to their existence but, the continuing existence of special schools indicates that they are accepted by the generality of society. The special schools alluded to can be defined as special because they provide for the education of people in a position to purchase a special education, or special because they cater for particular religious needs, and, although not an option by choice, special because they provide for the education of young people held in secure units as a result of criminal convictions. It can, therefore, be argued that if the concept that schools can be 'special' is not at issue then, in relation to disabled children, the issue must be the way special schools for disabled children have developed and how they function. If that line of discussion is followed then it can legitimately be argued that if special schools for disabled children performed a function which overcame the flaws in the present system, most notably, that of creating a negative self identity, then there could be a future role for such a system. However, special schools for disabled children, as discussed earlier, have been dominated by a medical model of disability. A consequence of this is that there has been a emphasis on the need to acquire 'social skills', but, as has been argued, this clearly has not equipped disabled young people to make the transition into the adult world beyond school. Therefore, it is difficult to envisage how the education profession could make the paradigm shift necessary to develop a special school system focused as much on developing a positive cultural identity as on academic attainment and the acquisition of skills. However, there examples which point to a way in which this barrier could be overcome.

If one examines the Danish education system, which encourages and funds diversity, then it can be seen how schools can provide a diverse range of

approaches linked to different theoretical concepts. It is not being suggested that Britain adopts the Danish system but that there is something to be said for having scope within the system for difference. Accordingly, special schools could follow the model established by centres for independent living whereby establishments and organisations are managed and largely operated by disabled people.

Centres organised by, and run by, disabled people have developed over the last two decades as a response by disabled people to services which neither included them in planning or collaborated with them on delivery, organisation, or control. As a result, groups of disabled people, frustrated by service providers who imposed inappropriate services on disabled people, established their own organisations in different parts of Britain. If one considers the early aims of such organisations, then it is not too great a leap of the imagination to see that if the same approach was taken to education then it is possible to see how special schools could have a positive future. Amongst the most well known inclusive living groups is the 'Derbyshire Centre for Inclusive Living'. The DCIL was formed by the Derbyshire Coalition of Disabled People, and if one considers their philosophy, when setting up the Coalition:

> 'It was taken as axiomatic that services should develop out of the direct experiences of disabled people.' Davis & Mullender (1993:30)

Furthermore, service delivery systems will only function in the interests of disabled people:

> 'when people who have personal experience of the daily problems of disability are themselves directly involved in service design, delivery, and control.' (Ibid:39)

Therefore, if special schools were managed by disabled people then it could be ensured that the overarching philosophy of the school was aimed at creating positive disabled identities. If one then extends the model so that schools are also the centre for support so that whilst the disabled child is at

school support for the parents is provided and then, as the disabled person matures into adulthood the support moves to the disabled person, thereby ensuring that parents can share the difficulties associated with the transition. So, it can be argued, special would not be an adjective for segregation, and the domination of disabled people by able bodied experts, but could become synonymous with the creation of a positive disabled identity, seamless support that provides for the needs of disabled children, disabled young adults, and parents. Disabled pupils would have positive role models of disabled people, and parents would also be able to work with disabled adults. Rather than their only experience of contact with disabled people being in hospital settings or as dependent and an individualised set of problems.

Disabled people need to be knowledgeable about a range of services and welfare rights. These are not necessarily needed by non-disabled people but tend to be integral elements in the life of a disabled person, Therefore, knowledge of those matters is as relevant for a disabled person as the acquisition of qualifications and personal skills. Consequently, special schools would become the site for advice of employing personal assistants and direct payments, welfare rights, advocacy, and a host of other services currently located in different settings. Obviously, this is a proposal which would require innovative and creative thinking from health, education, and social services, in collaboration with disabled people. Extreme caution would also need to be exercised to avoid such sites becoming 'ghettos' for disabled people, or mirroring the 'village community' concept, much maligned by disability rights activists. Consequently, care needs to be taken so that whilst services could be integrated, and the management located on site, the locations are included in the community. A further aspect of the strategy is that it is close to contemporary ideas about 'joined up government policies', 'seamless services', and multi-disciplinary working. Although the proposal could be seen as coming into conflict with New Labour's aspirations to tackle exclusion. This being one factor behind the Department for Education and Employment's Green Paper proposals to increase inclusion.

This should not be seen as a justification for perpetuating special education. It is a valid attempt to suggest that there could be an alternative to the present 'either - or' approach to special schools. It may be that the most appropriate way would be to follow the example of the way in which schools established to offer choice on the grounds of religious faith have developed. That is, on the basis that parents can choose to 'opt out' of mainstream provision. This would not, however, necessarily meet the broad aim of providing a seamless service, but it could, nevertheless, offer a way in which a positive approach to disability culture could be promulgated within the school curriculum. This would go some way to resolving the present situation, whereby it is acknowledged that the current system of special education is failing disabled young people. However, the range of evidence discussed earlier sheds much doubt that inclusion in mainstream schools would serve disabled children any better. Differently, yes, but better, doubtful. Equally, inclusion would offer little to parents, merely by shifting their disabled child from a special to a mainstream school would reduce their support and exacerbate the problems they currently experience. The proposal outlined above is a way of tackling the three key issues, parents, particularly mothers', need for support, the need for disabled children to develop a positive identity, and the transition from school into adulthood.

Furthermore, it would be better to take an active approach to special schools because, history suggests, they will probably persist in some form. Better to determine that that should be to the positive benefit of disabled people, and in their control, rather than leave it to the chance of market variables. It is clear that, for the Northern parents, 'the choice' is justified, because for them, and probably for other parents of a child with multiple and severe impairments, and those with speech and communication disorders, there is, and was, no choice. The special schools run by the Acorn Society, provide a crucial and essential foundation for many of the Northern parents. Nevertheless, the continued existence of special schools is under question, although there is

always the possibility that there will be examples of individual special schools opening to cater for specific needs. After all, the history of special education is evidence of the ability to survive. Furthermore, if one considers how the Acorn Society has developed facilities for children with autism over the 1990's so that they now feature as one of the strongest aspects of the services provided by the Society, then the ability of professional educators and service providers to perpetuate their own existence would suggest that special provision, at least within the charitable sector, will continue.

CONCLUSION

Special education and the effect it has on the shaping of a disabled person's identity has been the object of much research and discussion. The analysis provided by the social model provides a theoretical explanation of that role which is difficult to contest. Considerable research has also been carried out which demonstrates that the parents caring for a disabled child do not receive sufficient support. This has been shown to result in a variety of social, emotional, and financial costs, not experienced on the same scale by parents who do not care for a disabled child.

However, this thesis has avoided looking at the issue of special education simply from the perspective of the negative impact it is said to have on disabled children. Nor have parents been considered in isolation. What was recognised at an early stage in the research process was that previous research had not probed the connection between parents, special schools, and caring for a disabled child at home. Accordingly, this thesis has generated an analysis of the role of special education which places it within the wider experience of caring for a disabled child. By doing so, it has been demonstrated that previous research is largely guilty of either concentrating on parents' support needs in relation to how support is provided by agencies,

communities, and extended families; or concentrating on special schools solely in relation to disabled children.

Consequently, it has been argued, that special schools must be viewed in the light of the role they play in the lives of parents caring for a disabled child. And, whilst earlier research has identified gender differences, this research has clearly demonstrated that whilst it is women who provide the bulk of care, without the support of special schools the caring task would be even greater.

It has been shown throughout the thesis that theoretical approaches can explain the varying facets of special education, motherhood, disability, cultural identity, and social policy.

The analysis of relevant social policy initiatives and legislation identified that there is a framework within which sufficient support could be provided for parents caring for a disabled child. However, it was demonstrated that parents' experience of services is fragmented and lacking in continuity. Furthermore, the analysis demonstrated that agencies charged with the responsibility of providing support do not fulfil their obligations.

It is acknowledged that the Northern parents are a relatively small sample but the overall analysis of relevant literature indicates that their circumstances are not substantively different from those of other parents caring for a disabled child. The quality of the work with the Northern parents lies in how the breadth of their experiences were drawn out. This avoided the gaps highlighted in earlier research by taking a cross sectional approach which took a slice across s spectrum of experiences.

A proposal was made which explored how a more positive and active approach to special schools could see their role undergo fundamental changes. Because this goes against the grain of the social model and flies in the face of inclusionism the proposal is likely to face criticism for advocating

the perpetuation of segregation. However, the point has been put that in their existing form it is difficult to see how mainstream schools could meet the myriad emotional, cultural, educational, and physical needs of children with complex impairments. The proposal need not necessarily be seen as a blueprint for the future, but can be viewed as a medium term measure which could develop strategies and create a generation of disabled people with a positive view of their own cultural identity; whilst providing the kind of support parents need if disabled children and young people are to have a home life in which they can feel safe and supported.

The findings of this research and the proposals emanating from it are worthy of debate in a wider context and will help to broaden understanding of the complexities of caring for a disabled child along with the present, and future, role of special education in those lives.

A FINAL COMMENT

In the introduction to the thesis I referred to the research as being 'a journey'. The journey was described as having shifted my ideology. I am unsure if that is not overstating the position. I have certainly moved from a position whereby I saw the concept of special education as oppressive and, therefore, in need of abolition. However, my position is still that segregation, as it is currently operated in special schools for disabled children, should not be permitted in modern civil societies. Nevertheless, I now believe, as a consequence of my research with the Northern parents and the wider empirical work, that it is both impractical and unrealistic to assume that simply to abolish special schools would not, in itself, achieve the desired aim of an inclusive society. Perhaps it would, in time, but to push forward without any assurance that inclusion would resolve the social inequalities experienced by disabled people is a leap too far.

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Appendix A

Introductory letter

First questionnaire

Interview agreement

Dear Parent/s

Can I start by saying that I appreciate your reading this letter and I thank you for giving up a little of your time to do so.

The purpose of this letter is to introduce myself and to briefly explain why I am contacting you.

I am interested in how institutions like ***** have developed over time and why parents choose them for their sons and daughters. Because of this interest I am conducting a research project which is aimed at identifying the factors that influence you, as parents, in this choice. There were probably many considerations and factors that helped in the choice and I would be most grateful if you would help me to identify what they were.

I am, therefore, enclosing a questionnaire and if you could complete it and return it to me in the SAE I would be most thankful.

It is also my hope that some parents will agree to be interviewed by me at a later date so that I can clarify points that emerge from the questionnaire and also look in more depth at any issues that may emerge. If you are willing to be interviewed then would you complete the separate sheet to let me know who you are.

May I say again how much I appreciate the time you are taking and assure you that your responses will be treated in confidence.

Yours sincerely

John Lawson - Lecturer

QUESTIONNAIRE

A. Information on your daughter/son

1. Age ☐ years Sex (tick) ☐ female ☐ male

2. Name and address of previous school? .....
.....

3. Was this a special school? (circle) **Yes / No**

4. Has your daughter/son been statemented as having special educational needs? **Yes / No**

5. If '***Yes***' in what year ? ☐

6. Does your daughter/son board? (circle) **Yes / No**

7. How far does your daughter/ son travel to school? **1-2 2-3 3-4 4-5 More** ..... (specify)
(one way/miles - circle)

8. How long does the **0-30** min's **30-45** min's **45** min's **-1** hr **1- 1 1/2** hr's **1/2-2 hr's More** ..... (specify)
journey take? (circle)

9. What form of transport is used? (circle) **Private car Mini-bus Taxi Other** ..... (specify)

10. How would you describe your daughter/son's disability? .....
.....
.....
.....
.....

11. Does your daughter/son have personal care needs? **Yes / No**

If '***Yes***' how much time **0-30** min's **30** min's **- 1** hr **1- 1 1/2** hr's **1 1/2 - 2** hr's **More**..... (specify)
do you spend on those needs each day? (circle)

B About you and your family

12 What is the composition of your family? .....
[Please specify brothers & sisters, parents etc.] .....
.....
.....

QUESTIONNAIRE

Continued.....

13 Which of the following best describes your parents occupation? (tick)

	Your mother's	Your father's
Professional	.....	.....
Employer and/or manager	.....	.....
Non- manual, technical and administrative	.....	.....
Skilled manual	.....	.....
Semi-skilled manual/hotel/catering/ etc.	.....	.....
Unskilled manual	.....	.....
Unemployed	.....	.....

C. Choosing the school.

14. Did you receive advice from any of the following on which school to choose?	If *'yes'* tick	How much significance did you place on that advice/information? Most	A lot	Some	A little	None
Educational psychologist						
Head Teacher of previous school						
Social worker						
Consultant						
General practitioner						
Parents with children at the school						
Principals of potential colleges						
Physio(*or other*)therapist (specify)						
Other (specify).....						

15. Why did you choose ****? .....
.....
.....
.....
.....
.....

Please return in the enclosed SAE. Thank you for your co-operation.

I am willing to be interviewed

Name .....

Address .....

.....

.....;

.....Post Code..... .....

Telephone .....

		tick
I prefer to be contacted by:	**LETTER / TELEPHONE**	[ ]

The best time to telephone me is .....

Please return (along with the questionnaire) in the SAE

Appendix B

Revised questionnaire

QUESTIONNAIRE

A. Information on your daughter/son

1. Age ☐ years Sex (tick) ☐ female ☐ male

2. Name and address of previous school? .....
.....

3. Was this a special school? (circle) **Yes / No**

4. Has your daughter/son been statemented as having special educational needs? **Yes / No**

5. If '***Yes***' in what year ? ☐

6. Does your daughter/son board? **Yes / No**

7. How far does your daugher/ son travel to school? **1-3 4-6 7-10 11-14 15-18 More** .....
(one way/miles - circle) (specify)

8. How long does the **0-30** min's **30-45** min's **45** min's **-1** hr **1- 1 1/2** hr's **1/2-2 hr's More** .....
journey take? (circle) (specify)

9. What form of transport is used? (circle) **Private car Mini-bus Taxi Other** .....
(specify)

10. How would you describe your daughter/son's disability? .....
.....
.....
.....
.....

11. Does your daughter/son have personal care needs? **Yes / No**

If '**Yes**' how much time do you spend on those needs each day? (circle) **0-30** min's **30** min's - **1** hr **1- 1 1/2** hr's **1 1/2 - 2** hr's **More**.....
(specify)

B About you and your family

12 What is the composition of your family? .....
[Please specify children & ages/partners etc.] .....
.....
.....

Appendix C

First interview schedule

1. WHEN AND HOW DID YOUR SON/DAUGHTER COME TO BE STATEMENTED?

2. HOW DID YOU LEARN ABOUT STATEMENTING?

3. HOW DID YOU FEEL ABOUT THE PROCESS?

4. WHEN AND HOW DID YOU CONCLUDE THAT YOUR SON/DAUGHTER WOULD NEED TO GO TO A SPECIAL SCHOOL?

5. WHO WAS INVOLVED IN THAT DECISION?

6. HAVING DECIDED THAT A SPECIAL SCHOOL WAS NECESSARY HOW DID YOU GO ABOUT SELECTING WHICH ONE?

7. WHICH PEOPLE WERE INVOLVED AND HOW SIGNIFICANT WAS THEIR INPUT?

8. WOULD YOU PREFER A MAINSTREAM SCHOOL IF ADEQUATE CARE OR PARA-MEDICAL INPUT WERE AVAILABLE?

9. DO YOU FEEL THAT YOU HAD SUFFICIENT CHOICES AVAILABLE TO YOU?

10. HOW DO YOU FEEL ABOUT THE BALANCE BETWEEN CARE/SUPPORT AND EDUCATIONAL GOALS?

11. IS THE LEVEL AND NATURE OF THE SUPPORT YOU RECEIVE FROM THE SCHOOL DIFFERENT TO THAT FROM A MAINSTREAM SCHOOL?

12. DO YOU FEEL THAT IT HELPS YOU TO COPE WITH THE ADDITIONAL DEMANDS OF CARING FOR YOUR SON/DAUGHTER?

13. HAVE YOU HAD ANY CONTACT WITH YOUR SOCIAL SERVICES DEPARTMENT?

14. DO YOU RECEIVE ANY ASSISTANCE FROM SOCIAL SERVICES?

15. WHAT FORM DOES THE ASSISTANCE/HELP/SUPPORT TAKE?

[IF NO CONTACT WITH SSD]

16. a. ARE YOU AWARE OF THE DUTIES OF SSD's IN RELATION TO 'CHILDREN IN NEED' I.E. DISABLED CHILDREN?

b. DO YOU THINK YOU WOULD BENEFIT FROM SOCIAL SERVICES SUPPORT?

17. HOW DO YOU PERCEIVE THE LONG TERM POTENTIAL OF YOUR SON/DAUGHTER IN RELATION TO WHAT THEY WILL DO WHEN THEIR TIME AT SCHOOL FINISHES?

18. a. DO YOU THINK THAT HAVING A CHILD WITH SPECIAL NEEDS HAS HAD ANY IMPACT ON THE FAMILY AS A WHOLE?

    b. IN WHAT WAY AND WHY?

19. COULD THERE BE ANY SUPPORT PROVIDED THAT WOULD HAVE BEEN OF BENEFIT?

YOUNG PEOPLE 14 & OVER

20. HAVE ANY DISCUSSIONS TAKEN PLACE REGARDING PLANNING FOR SCHOOL LEAVING?

21. HOW INVOLVED ARE YOU AND YOUR SON/DAUGHTER IN THE PLANNING PROCESS?

22.

MOTHERS ONLY

23. DO YOU FEEL THAT HAVING TO CARE FOR YOUR SON/DAUGHTER HAS IMPACTED ON YOUR CAPACITY TO PURSUE PERSONAL OBJECTIVES?

24. DOES YOUR PARTNER TAKE AS ACTIVE A ROLE IN THE LIFE OF YOUR DISABLED SON/DAUGHTER AS THE OTHER CHILDREN IN THE FAMILY?

25. DO YOU FEEL THAT THERE IS A GREATER EXPECTATION PLACED ON YOU IN RELATION TO YOUR DISABLED CHILD?

26. DO YOU FEEL THAT YOUR OBLIGATION TO YOUR DISABLED SON/DAUGHTER IS DIFFERENT THAN THAT OF YOUR OTHER CHILDREN?

27. DO YOU THINK THAT YOUR PARTNER WOULD BE PREPARED TO SPARE A LITTLE TIME TO TALK TO ME?

Appendix D

Revised interview schedule.

1. WHEN AND HOW DID YOUR SON/DAUGHTER COME TO BE STATEMENTED?

2. HOW DID YOU LEARN ABOUT STATEMENTING?

3. HOW DID YOU FEEL ABOUT THE PROCESS?

4. WHEN AND HOW DID YOU CONCLUDE THAT YOUR SON/DAUGHTER WOULD NEED TO GO TO A SPECIAL SCHOOL?

5. WHO WAS INVOLVED IN THAT DECISION?

6. HAVING DECIDED THAT A SPECIAL SCHOOL WAS NECESSARY HOW DID YOU GO ABOUT SELECTING WHICH ONE?

7. WHICH PEOPLE WERE INVOLVED AND HOW SIGNIFICANT WAS THEIR INPUT?

8. WOULD YOU PREFER A MAINSTREAM SCHOOL IF ADEQUATE CARE OR PARA-MEDICAL INPUT WERE AVAILABLE?

9. DO YOU FEEL THAT YOU HAD SUFFICIENT CHOICES AVAILABLE TO YOU?

10. HOW DO YOU FEEL ABOUT THE BALANCE BETWEEN CARE/SUPPORT AND EDUCATIONAL GOALS?

11. IS THE LEVEL AND NATURE OF THE SUPPORT YOU RECEIVE FROM THE SCHOOL DIFFERENT TO THAT FROM A MAINSTREAM SCHOOL?

12. DO YOU FEEL THAT IT HELPS YOU TO COPE WITH THE ADDITIONAL DEMANDS OF CARING FOR YOUR SON/DAUGHTER?

13. HAVE YOU HAD ANY CONTACT WITH YOUR SOCIAL SERVICES DEPARTMENT?

14. DO YOU RECEIVE ANY ASSISTANCE FROM SOCIAL SERVICES?

15. WHAT FORM DOES THE ASSISTANCE/HELP/SUPPORT TAKE?

[IF NO CONTACT WITH SSD]

16. a. ARE YOU AWARE OF THE DUTIES OF SSD's IN RELATION TO 'CHILDREN IN NEED' I.E. DISABLED CHILDREN?

b. DO YOU THINK YOU WOULD BENEFIT FROM SOCIAL SERVICES SUPPORT?

17. HOW DO YOU PERCEIVE THE LONG TERM POTENTIAL OF YOUR SON/DAUGHTER IN RELATION TO WHAT THEY WILL DO WHEN THEIR TIME AT SCHOOL FINISHES?

18. a. DO YOU THINK THAT HAVING A CHILD WITH SPECIAL NEEDS HAS HAD ANY IMPACT ON THE FAMILY AS A WHOLE?
    b. IN WHAT WAY AND WHY?

19. COULD THERE BE ANY SUPPORT PROVIDED THAT WOULD HAVE BEEN OF BENEFIT?

YOUNG PEOPLE 14 & OVER

20. HAVE ANY DISCUSSIONS TAKEN PLACE REGARDING PLANNING FOR SCHOOL LEAVING?

21. HOW INVOLVED ARE YOU AND YOUR SON/DAUGHTER IN THE PLANNING PROCESS?

22. DO YOU CONSIDER YOURSELF TO BE YOUR SON/DAUGHTER'S ADVOCATE?

23. DO YOU FIND THAT YOU MAKE DECISIONS ON YOUR SON/DAUGHTER'S BEHALF - HOW DO YOU FEEL ABOUT TAKING THAT RESPONSIBILITY?

MOTHERS ONLY

24. DO YOU FEEL THAT HAVING TO CARE FOR YOUR SON/DAUGHTER HAS IMPACTED ON YOUR CAPACITY TO PURSUE PERSONAL OBJECTIVES?

25. DOES YOUR PARTNER TAKE AS ACTIVE A ROLE IN THE LIFE OF YOUR DISABLED SON/DAUGHTER AS THE OTHER CHILDREN IN THE FAMILY?

26. DO YOU FEEL THAT THERE IS A GREATER EXPECTATION PLACED ON YOU IN RELATION TO YOUR DISABLED CHILD?

27. DO YOU FEEL THAT YOUR OBLIGATION TO YOUR DISABLED SON/DAUGHTER IS DIFFERENT THAN THAT OF YOUR OTHER CHILDREN?

28. DO YOU THINK THAT YOUR PARTNER WOULD BE PREPARED TO SPARE A LITTLE TIME TO TALK TO ME?

Appendix E

Oak College

Introductory letter

Adaptec questionnaire

Interview agreement

HEADED PAPER

Dear Student and Parent/s

Can I start by saying that I appreciate your reading this letter and I thank you for giving up a little of your time to do so.

The purpose of this letter is to introduce myself and to briefly explain why I am contacting you.

I am interested in how establishments like ***** have developed over time, why students select them, and why parents choose them for their sons and daughters. Because of this interest I am conducting a research project which is aimed at identifying the factors that influence you, as a student and your parents, in this choice. There were probably many considerations and factors that helped in the choice and I would be most grateful if you would help me to identify what they were.

I am, therefore, enclosing a questionnaire and if you could complete it and return it to me in the SAE I would be most thankful.

It is also my hope that some parents of students at ***** will agree to be interviewed by me at a later date so that I can clarify points that emerge from the questionnaire and also look in more depth at any issues that may emerge. If you are willing to be interviewed then would you complete the separate sheet to let me know who you are.

It is also my hope that I will be able to hold discussions with students at the College so I will be discussing how this might best be facilitated with *** ******. I hope that you, as a student of *****, will be agreeable to this.

May I say again how much I appreciate the time you are taking and assure you that your responses will be treated in confidence.

Yours sincerely

John Lawson - Lecturer

PARLETI 6 95

QUESTIONNAIRE

A. Personal Information

1. Age ☐ years Sex (tick) ☐ female ☐ male

2. Name and address of previous school? .....
.....

3. Was this a special school? (circle) **Yes / No**

4. Have you been statemented as having special educational needs? **Yes / No**

5. If '***Yes***' in what year ? ☐

6. How far do you travel to collegel? (one way/miles - circle) **1-3 4-6 7-10 11-14 15-18 More** ..... (specify)

7. How long does the journey take? (circle) **0-30** min's **30-45** min's **45** min's -**1** hr **1- 1^1/$_2$** hr's **^{1}/$_2$-2 hr's More** ..... (specify)

8. What form of transport is used? (circle) **Private car Mini-bus Taxi Other** ..... (specify)

9. How would you describe your disability? .....
.....
.....
.....
.....

10. Do you have personal care needs? **Yes / No**

    If '***Yes***' how much time do these require each day? (circle) **0-30** min's **30** min's - **1** hr **1- 1^1/$_2$** hr's **1^1/$_2$ - 2** hr's **More**..... (specify)

B About you and your family

11 What is the composition of your family? .....
[Please specify brothers & sisters, parents etc] .....
.....
.....

Continued.....

QUESTIONNAIRE

12 Which of the following best describes your parents occupation? (tick)

	Your mother's	Your father's
Professional	.....	.....
Employer and/or manager	.....	.....
Non- manual, technical and administrative	.....	.....
Skilled manual	.....	.....
Semi-skilled manual/hotel/catering/ etc.	.....	.....
Unskilled manual	.....	.....
Unemployed	.....	.....

C. Choosing a college.

13. Did you consider other colleges? (circle) **Yes / No**

14. If '**Yes**' how many? (circle) **1** **2** **3** **4** **More** (specify) .....

15. How many did you visit personally? (specify) .....

16. Did you receive advice from any of the following on which school to choose?	If *'yes'* tick	How much significance did you place on that advice/information?				
		Most	A lot	Some	A little	None
Educational psychologist						
Head Teacher of previous school						
Social worker						
Consultant						
General practitioner						
Parents with children at the school						
Principals of potential colleges						
Physio(*or other*)therapist (specify)						
Other (specify).....						

17. Why did you choose *****? .....
.....
.....
.....
.....

Please return in the enclosed SAE. Thank you for your co-operation.

*Parents of students at ***** College*

I am willing to be interviewed

Name .....

Address .....

.....

.....;

.....Post Code..... .....

Telephone .....

		tick
I would prefer to be interviewed	[a] **IN PERSON**	[ ]
	[b] **BY TELEPHONE**	[ ]

The best time to telephone me is .....

Please return (along with the questionnaire) in the SAE *- thankyou*

Appendix F

Criteria applied, and data compiled, by 'Sophie' and partner when they were choosing a school.

SCHOOL A

FOR

Reasonable travelling distance..

Small comfortable unit.

Good area - re friendships and fathers occupation.

Well established within school.

AGAINST

Insufficient Speech Therapy.

Very limited integration.

Disruption to stability at 7 years.

Staff did not appear enthusiastic.

Children in the unit with different problems to Christopher,not particulaly speech probl

Poor educational plans.

Specialises in Moderate Learning difficulties, not Language dilsorders.

SCORE 2, 4, 0, 6, 8, 4, 3, 9, 9, 9. Total 53 points.

SCHOOL B

FOR

Small comfortable unit.

Good unit / school enviroment.

Well established within the school.

Good integration plans.

Reasonable mixture of childrens problems.

Keen staff.

Reasonable area.

AGAINST.

Insufficient Speech Therapy, ($\frac{1}{2}$ day on mainly advisory basis only.)

Has to leave at 7 years.

Poor prospects for making friends.

Moderate Learning difficulties unit, does not specialise in Language problems.

SCORE 0, 6, 0, 9, 8, 5, 8, 7, 7, 9. Total 59 points.

SCHOOL C

FOR

Good Speech Therapy, constantly available.

All children have like problems.

Can stay to 11 years.

Sound teaching practices and educational planning.

Enthusiastic and caring staff.

Good integration.

Well established within the school.

Friendly happy enviroment.

Good area.

AGAINST

Distance, - not particularly local. (4 miles)

Poor prospects for making friends, but not out of the question.

SCORE 10, 8, 10, 10, 8, 8, 8, 9, 7, 10. Total 88 points.

List of Priorities.

1. Amount of Speech Therapy available.
2. Opportunities for Integration.
3. Stability to 11 years.
4. Good / Caring teachers and staff.
5. Happy Unit and School enviroment.
6. Unit with children with like problems.
7. Educational plans - levels of achievment.
8. Appropriatness of area. Re possible friendships, and fathers occupation.
9. Travelling distance from home address.
10. Staff / pupil ratio.

SCHOOL D

FOR

Small Unit enviroment.

Good / enthusiastic staff.

AGAINST

Insufficient Speech Therapy.

Insufficient integration with peer group.

Disruption to routine at 7 years.

Other childrens problems to different to that of Christophers.

Poor Educational prospects.

Locality - Unsuitable area both for making friendships and with regard to fathers

Situated to far from home address.

Schools priority is to that of children with learning difficulties, not Language prob

SCORE 2, 2, 0, 7, 5, 3, 4, 0, 0, 9. Total 32 points.